To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?

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DECLARATION

'I certify that the work contained in this thesis, or any part of it, has not been accepted in substance for any previous degree awarded to me or any other person, and is not concurrently being submitted for any other degree other than that of the Degree of Doctor of Philosophy which has been studied at the University of Greenwich, London, UK.

I also declare that the work contained in this thesis is the result of my own investigations, except where otherwise identified and acknowledged by references. I further declare that no aspects of the contents of this thesis are the outcome of any form of research misconduct.

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ABSTRACT

To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?

Roma people throughout Europe appear to experience high levels of infant mortality and short life expectancy, with poor living conditions and ongoing discrimination impacting negatively on health and well-being, in particular on mental health. However, literature focusing specifically on Roma health in the UK is limited, with most surveys noting a lack of research in this area. Across the UK, policy and planning to meet the specific healthcare needs of Roma communities is sparse and inconsistent, including the response to the requirements of the EU Framework for National Roma Integration Strategies up to 2020. Similarly, monitoring by ethnicity of Roma people across the UK remains inadequate, resulting in a lack of data regarding Roma health and well-being.

This qualitative study examines the health and well-being experiences of members of Roma communities, through semi-structured individual interviews carried out in three London boroughs. Using concepts such as voice, culture, identity, agency and nomadism, from a post-structuralist theoretical perspective, the study seeks to explore the wide range of narratives impacting on Roma health and well-being in London and across the UK.

The findings locate the health and well-being experiences of Roma people in London in the context of migration to a new country, with Roma culture seen to be both traditional and adapting to change. Wide-ranging experiences, both positive and negative, reflecting those of members of many other communities, were reported. Using processes of identification with non-Roma people, participants repositioned themselves in relation to marginalising discourses. The findings suggest that categorising Roma people as ‘hard to reach’ further marginalises them in relation to services and outcomes. This study contributes to a rethinking of Roma health and well-being in the UK, that challenges essentialising constructions and moves from a focus on the past, into the present and towards the future.

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INTRODUCTION

1.1 Vignette

Before beginning this project, whist I was still working in my previous employment, a colleague and I encountered a family of old friends. Called to a meeting at a school, to resolve a problem that had arisen with a young Irish Traveller pupil, I met a family I had worked with for many years when I ran a Traveller Education Support Service in a London borough. It was as though nothing had changed, although I was by this time in a different borough and a different job, and the meeting was somewhat hijacked by our delight at seeing one another, and our reminiscing.

It transpired that this large, extended family now lived close to the school and my colleague and I were invited home to see the matriarchal grandmother and drink tea. The invitation was accepted, my colleague was introduced, as the person who would continue to support their child after my departure, and they asked where I was going. I tried to explain but, initially, they didn't really understand what it was I was going to do. They thought, at first, I was going back to working with the English Romanichal Gypsies, with whom they knew I had worked before. Then, they thought I was going to work in another country. But finally, a daughter-in-law acted it out. Rubbing her belly, and holding out her hand in a begging gesture, she said, 'Feed me, feed me; baby hungry', and everyone knew exactly who I was going to be working with.

That morning felt like the real beginning of the project, far more than applications and interviews and resignations. I was back with the Gypsy, Roma and Traveller communities, where a tiny scenario can shed more light on events than a library of books might. It wasn't necessary to be literate to know that Roma families are viewed stereotypically as beggars. Even this struggling family, subject to the prejudices commonly expressed towards both Travellers and the Irish, felt themselves to be superior to the Roma.

1.2 Terminology

The Council of Europe (March 2017) offers the following definition regarding terminology:

> The term "Roma and Travellers" is used at the Council of Europe to encompass the wide diversity of the groups covered by the work of the Council of Europe in this field:

> on the one hand a) Roma, Sinti/Manush, Calé, Kaale, Romanichals, Boyash/Rudari; b) Balkan Egyptians (Egyptians and Ashkali); c) Eastern groups (Dom, Lom and Abdal); and, on the other hand, groups such as Travellers, Yenish, and the populations designated under the administrative term "Gens du voyage", as well as persons who identify themselves as Gypsies.

Despite the often contradictory, and sometimes contested, definitions of the term 'Roma', the present study focused only on Roma individuals, who had migrated to the UK from Central and Eastern Europe, and who self-identified as being of Roma heritage. Following Hancock (2002), the term 'Romani' is used in the present study to describe the worldwide collectivity to which Roma groups belong. When discussing the totality of peoples referred to in the definition above, the collective term 'Gypsy, Roma and Traveller' is used. In this context, 'Gypsy' refers to members of the Romani communities living in the UK since the 16th century – Romanichals and Welsh Kale (Fraser, 1995). The term 'Traveller' refers to members of communities of Scottish and Irish origin, minority ethnic groups identified very closely with a nomadic lifestyle (ibid.).

1.3 Background

Since the eighteenth century, historical, linguistic and genetic research has led many scholars to the conclusion that the Romani people can trace their origins to Northwest India, leaving between the tenth and twelfth centuries (Hancock, 2008, 2002; Fraser, 1995). From here, the ancestors of modern Romanies migrated through Persia, Armenia, Greece and the Balkans, reaching Western Europe in the fifteenth century (Fraser, 1995). The first record of Romanies in Britain is in a Scottish document, dated 1505 (ibid.).

In addition to debate about dates, there is disagreement about the group, or groups, leaving and the number of languages spoken at the time of departure. The linguist and Romani scholar, Ian Hancock, believes that a number of ethno-linguistic populations left India and that it was only after reaching, and settling in, Anatolia that the language of the Romanies developed: 'There *were* no Roma before Anatolia' (Hancock, 2008: 12, original italics).

In this regard, Hancock (ibid: 13) offers an explanation for some of the confusion around identities that continues to exist, in relation to this collectivity:

> Because the population was fragmenting and moving into Europe during the very period that an ethnic identity was emerging, there is no sense of having ever been a single, unified people in one place at one time. We can speak of a "core of direct retention" consisting of genetic, linguistic and cultural factors traceable to Asia and

> evident to a greater or lesser extent in all populations identifying as Romani, but we must also acknowledge that all of these areas have been augmented too through contact with European peoples and cultures, and it is the latter accretions that account for the sometimes extreme differences from group to group.

The linguist, Yaron Matras, on the other hand, thinks that the language of the Romani people was formed inside India and that one people left, speaking one language (Margalit and Matras, 2007). Fraser (1995), however, on a number of occasions, cautions against making unfounded assumptions from the linguistic evidence:

> Indubitably, the study of Romani can reveal a great deal about the origin and evolution of the language itself. How far that can be equated with the origin and evolution of Romani-speakers is a more speculative matter, and the equivalence cannot be taken for granted (ibid: 10).

And:

> So long, however, as it remains impossible to narrow the options of time and place, there will still be plenty of room for dispute as to exactly who, in terms of caste, occupation and ethnic origin, left the Indian subcontinent a thousand years or more ago, and whether or not they left as a single group (ibid: 28).

Despite these uncertainties, there is little dispute with regard to the degree to which Romani people, including Roma groups, have faced persecution and discrimination since the sixteenth century. Thomas Acton (2004: 106) states that, '...for the first century of Romani migration into western Europe, the attitude to them was an open and enquiring one, very different from what it was to become'. Following Fraser (1995), Acton (2004) dates the arrival of the Romanies in western Europe to the early fifteenth century (ibid.). The period between 1530 and 1550 saw the development of the nation-state across Europe, which led to the negative defining of foreigners and heretics. At the same time, the rise of agricultural capitalism produced hostility towards vagrants (ibid.). Attitudes towards vagrants became more hostile than those towards foreigners, and Romanies, at this time, found themselves included within the category of vagrants. Romanies were seen as feigning an 'exotic' history, and their claims to have a language of their own were dismissed. The language they used was deemed to be secret, made-up slang, used by the Romanies to disguise criminal activity (ibid.).

This situation continued and worsened throughout the sixteenth and seventeenth centuries, when a series of Acts of Parliament were passed in Britain, in an attempt to force itinerant people into 'respectable' settlement. Angus Fraser (1995: 138) writes that, alongside the attempt to force anyone living ‘an idle and vagrant life’ to be rehabilitated, the living of such a life by those deemed a foreigner was punishable by death. In 1562, Elizabeth 1 passed, ‘an Act “for further Punishment of Vagabonds, calling themselves Egyptians”’ (ibid: 131). In Scotland, in 1609 under James VI, ‘an “Act anent the Egiptians”’ also made it lawful to condemn and execute Romanies (ibid: 137).

Fraser (ibid: 126) notes ‘a fairly consistent pattern as Gypsies spread over virtually the whole of Europe.’ He states that signs of rejection of Romanies appear quite soon after their arrival in a country, with ‘[t]he first edicts of generalized application…issued anything from a few decades to a century or more after their first arrival…, even if expulsion and repression have not yet quite become universal throughout Europe’ (ibid: 126). Fraser (ibid: 129) suggests that ‘[f]or the next 200 years and more – from the mid-sixteenth to the latter part of the eighteenth century – there is a depressing uniformity about the response of most European powers to the presence of Gypsies’. Romani people continued to be both criminalised and racialised, although Fraser (ibid.) notes that, had all the laws existing against them been enforced without compromise, Romanies would have been eradicated from much of Christian Europe before the mid-sixteenth century.

The insecure position of landless Romani groups in Europe led to horrifying outcomes, including enslavement in the Balkans from the fourteenth to the nineteenth century; in England, Spain and Portugal during the sixteenth century; and in eighteenth century Russia and Scotland (Hancock, 2002). Records from the fourteenth century show Romanies enslaved to the princes and monasteries of what are now Romania and Moldova (ibid.). Hancock (ibid.) notes that it was not until 1864, after Romania had been created as a separate country, that total legal freedom for the Romanies came about.

However, ‘[t]he greatest tragedy to befall the European Romani population was the attempt to eradicate it as part of the Nazis’ plan to have a “Gypsy-free” Europe’ (ibid: 34). Alongside Jewish communities, Roma and Sinti (a Romani people) were singled out for annihilation by the National Socialist Party on the basis of their ethnicity. Like Jews, as foreigners they were believed to pose a threat to German ‘racial purity’ and those of mixed heritage were particularly despised. Hancock (ibid.) suggests that between a half-million and a million-and-a–half Roma and Sinti were murdered in Nazi Germany and occupied Europe and believes that this number may be a gross under-estimate. The struggle for recognition, recompense and education with regard to this period of their history is, for the Roma and Sinti communities, quite recent and ongoing.

In relation to contested constructions of Roma people, Huub van Baar (2011a) considers a more recent exchange between scholars in the field of Romani Studies and linguistics, regarding the origins and language of the Romani people. Despite the early mistrust of Romani people's asserted Indian origins (Acton, 2004), during the 18th century a series of Western European studies attempted to answer questions about the identity of the groups of people living in countries across Europe, popularly known as 'Egyptians' (Gypsies) or 'Tsingani' (Grellmann, 1783, translated 1787; Rüdiger, 1782; Pray, 1776 [Hancock, 2002]). Whilst these studies varied in their quality, motivation and methods, together they linked the language spoken by Romani people in Europe to Sanskrit and, consequently, to the conclusion of an Indian origin (Hancock, 2002). Hancock (ibid.) dates the beginning of Romani Studies to this time.

This view prevailed, certainly within the Romani Studies field, until it was challenged by a group of Dutch academics (Lucassen et al., 1998; Willems, 1997; Lucassen, 1990), following earlier similar thinking by Judith Okely (1983). Wim Willems and his colleagues suggested that the supposed Indian origin of the Romani people was a construct without solid proof and, moreover, one that had harmed this collectivity. Willems (1997) believed that the development of racism towards Gypsies, from the Enlightenment to the Nazi era, culminating in the use of so-called 'racial science' during the Holocaust, was based on the ethnic identity conferred on Gypsies as a result of studies by those he describes as 'Gypsyologists', including Heinrich Grellmann (1787) and George Borrow (1924). Willems' solution was to question the validity of these studies and any connections made between Gypsies, their language and India (ibid.).

In his writing, Willems ignored or downplayed the linguistic evidence for links with India (ibid.). This challenge to the idea of an Indian origin of Romani people supported by Fraser (1995), and by Hancock (2008) and Matras (2004), albeit with differences between them, was contested by Matras (2004), arguing on the basis of the academic specialism of linguistics, and the linguistic evidence linking the Romani language to Indian languages.

Despite the apparently irreconcilable epistemological differences between these two perspectives, van Baar (2011a) concludes that differently socially constructed theoretical discourses can be viewed alongside each other to illuminate the process of the 'discovery' of the now taken-for-granted idea of Romani ethnicity. The work of van Baar (ibid.), also a Dutch scholar, offers an overview of the modern construction of the Roma as a European transnational minority, and bridges the epistemological divide between Willems and Matras. For the Roma, contemporary Europe, including the UK, is the location of the current political and ideological struggles, within which they find themselves subject to the multiple influences of techniques of modern governance (ibid.).

The Roma Integration 2020 website (11th September 2017) notes that the Roma are the largest ethnic minority within Europe and are mostly marginalised and vulnerable. Quoting the EU, it adds, 'Of an estimated 10-12 million in the whole of Europe, some six million live in the EU, most of them EU citizens' (ibid.). Since the fall of the Soviet Union in 1991, the Roma – Romani people living in Central and Eastern Europe – have been constructed by the EU as a transnational European minority. The earlier focus on nomadism and assimilation has shifted to one of 'improvement' and integration (van Baar, 2011a). Van Baar (ibid.) notes that, in Central and Eastern Europe, prejudice towards the Roma has increased as countries formerly within the Soviet Union have struggled to adjust to capitalist economies. Within the EU, despite their legitimate status as citizens of EU Member States, Roma continue to be regarded as 'outsiders', and to be distrusted. This negative portrait is reinforced by much of the media throughout the whole of Europe, and by right-wing political parties in Central and Eastern Europe (France 24, 2016; Gilligan, 2015; Jovanovic, 2015).

Van Baar (2018, 2011a) has described the unique place in contemporary Europe occupied by the Roma, where they are the subjects of innumerable strategies and interventions directed at combating discrimination and improving their living conditions and life opportunities whilst, at the same time, trying to push them into a more 'governable' mainstream cultural position. Van Baar (2018: 14) considers the intersectional relationship between development and security practices and suggests that: '…the ways in which the biopolitics of development intersects with the intra-European geopolitical conditions of contained mobility have resulted in a situation in which, for the poorest among the Roma, it has become increasingly more difficult to escape poverty and societal isolation.'

For example, the Decade of Roma Inclusion (2005 – 2015) was an initiative involving a group of Central and Eastern European (CEE) countries, and Spain, in a programme designed to eliminate discrimination against the Roma, and to close the gaps between the Roma and other citizens in the areas of education, employment, health and housing (Roma

Integration 2020 website). This programme, initiated and supported by the Open Society Foundations (OSF) and the World Bank, raised awareness of the problems facing the Roma, including the issue of poverty, but failed to achieve significant change for Roma communities in the countries involved (ibid.). Zeljko Jovanovic (2015: 1), reporting on the failure of the Roma Decade, notes that '...today there is more money, but less political will'. Jovanovic (ibid: 4) stresses the need to include 'the excluded and the exploited' in the process of setting goals for public institutions and the use of public funds if real change is to take place.

As a result of this initiative, in 2011 the European Commission adopted 'An EU Framework for National Roma Integration Strategies up to 2020' (NRIS). This called on all EU Member States to prepare a strategy to address Roma inclusion in the same four areas as those identified for the Decade of Roma Inclusion (Roma Integration 2020 website). However, the UK response to the requirement for an NRIS was extremely limited and lacked commitment (Fekete, 2015, European Commission, 2014b; Lane et al., 2014; Ryder and Cemlyn, 2014; Willers and Greenhall, 2012; van Baar, 2011a).

The midterm review of the EU framework for NRIS (European Commission, 2017) reported some improvements in the area of education, but little improvement in the other key areas, including health. Across the EU as a whole, a lack of basic medical insurance coverage continued to prevent many Roma from accessing healthcare services. However, improvements in health awareness and access to vaccinations, medical check-ups, pre- and post-natal care and family planning were reported. The report also suggested a link between improved self-perception of health status by Roma individuals and a fall in the number of Roma suffering regularly from hunger. There was no specific mention of the UK in this report, in relation to any of its aspects (ibid.).

The midterm review prioritised strengthening anti-discrimination measures, in order to combat anti-Gypsyism across the four key policy areas for both the EU Framework and the NRIS. It noted that: 'Fighting antigypsyism and stereotypes by **targeting majority society** is a pre-condition for generating political will and for the success of any Roma inclusion intervention' (ibid: 17, original emphasis). The OSF (Open Society European Policy Institute, 2017: 23) highlighted the centrality of anti-Gypsyism and suggested that measures to support inclusion and integration of Roma individuals could not be successful without a significant challenge to 'the deeply rooted racism in European societies and institutions'.

Between 1989 and 2004/2007, Roma individuals and families sought asylum in the UK on the grounds of discrimination and persecution experienced within their home countries (Roma Support Group (RSG), 2012). 2004 saw the expansion of the EU, to include the CEE countries referred to as the A8 countries, some of these – Poland, the Czech Republic, Slovakia and Slovenia – having relatively high Roma populations (ibid.). In 2007, further expansion of the EU included the A2 countries, Bulgaria and Romania, although with heavy restrictions on the right to work (ibid). In 2014, these restrictions were lifted, allowing Bulgarian and Romanian migrants the freedom to live and work in the UK. These two countries also have significant Roma populations (Performance and Research Team, Sheffield City Council, 2015).

Consequently, under the terms of the EU Free Movement Directive (Official Journal of the European Union, 2004/58/EC), Roma individuals and families in all EU countries have the same rights as other citizens to move within the EU, notwithstanding the political debates that have ensued regarding these rights more generally (O'Nions, 2014). Many have made the journey from Central and Eastern Europe to live in Western European countries, including the UK. Establishing the number of Roma people currently living in the UK is problematic, due to variation in monitoring by ethnicity in the different countries (Ryder and Cemlyn, 2014). One estimate suggests a UK population of around 300,000 Roma individuals (Equality website, 2017).

The Free Movement Directive states that '[p]ersons exercising their right of residence should not, however, become an unreasonable burden on the social assistance system of the host Member State during an initial period of residence. Therefore, the right of residence for Union citizens and their family members for periods in excess of three months should be subject to conditions' (Official Journal of the European Union, 2004/58/EC: item 10). In order for the right of residence to exceed three months, EU citizens must exercise one of the four Treaty rights, by working as an employee, working as a self-employed person, studying or being self-sufficient or retired. This condition has seen many Roma people, unable to find paid work and turning to begging to support their families, deported from the UK, begging being increasingly constructed as a criminal activity (Walker, 2015).

In addition, many Roma individuals are forced to work in what Hufton referred to as 'the economy of makeshifts' (Hufton, 1974). Verdon (2002: 166) notes, 'Hufton's definition of a makeshift economy embraced "innumerable forms of subsidiary income" such as an additional job or seasonal migration to find work'. Hufton's understanding of the role of women, in particular mothers, in preventing families from falling into poverty translates perfectly to the role played by many Roma women, who have used begging, or selling of 'The Big Issue' magazine, to supplement the precarious income of Roma men who are often employed in agriculture, contract cleaning, fast food outlets, or the construction industry (Walker, 2015). This scenario, together with the homelessness or unstable housing that often accompanies it, does little to provide for easy and consistent access to health care or other services, which have been set up to cater for a sedentary and stable population.

Despite the association, through negative media and political discourse, of Roma migrants from the EU with 'benefit tourism', Martin et al. (2017) found that the main motivation for Roma migration to the UK was easier access to work opportunities, which were frequently denied to Roma people in Central and East European countries. Whilst work obtained in the UK is often precarious, with harsh and exploitative conditions, the findings of Martin et al. (ibid: 10) suggested that '…work was fundamental to supporting the family, but also that work is desirable in of [sic] itself, with work often seen as the gateway to achieving a sense of belonging'.

Nevertheless, 'Roma are increasingly racialized in specific policy measures to discourage their settlement in receiving countries' (Morell et al., 2018). Greenfields and Dagilyte (2018) note that obstacles encountered by Roma people claiming in-work welfare benefits in the UK amount to a form of tacit 'bordering', and Nagy (2018) describes social exclusion, in the form of negative judgements, based on the type of economic activity undertaken by Roma migrants. Whilst migration to the ethnically diverse cities of the UK can appear to offer Roma people an escape from the racialisation associated with the high visibility of their ethnicity in their countries of origin, this is encountered in new, perhaps more subtle, forms (Grill, 2017). Living and working conditions for Roma migrants to the UK remain precarious, with negative implications for their health and their well-being.

Jan Grill (2012) describes the experiences of Slovakian Roma migrants to the UK, following 2004 when Slovakia joined the EU. Grill (ibid: 1269) notes that, through the idea of 'going up', both geographically and socially, these Slovak Roma people expressed their desire that migration might offer them a possible means of making a new and better life, based on their own autonomy and enabling them to leave behind, to some degree, inequalities experienced in their home country both in relation to non-Roma dominant groups and non-related Roma.

Using an ethnographic approach, Grill seeks to '…emphasis[e] the centrality of ethnography for conceptualising migration trajectories in terms of transnational social fields or migration circuits' (ibid: 1270). Grill's work brings together the complex relationships between the socio-historical contexts in which Roma migration takes place, the hopes and imaginings of Roma people in relation to migration, and the concrete experiences, combining successes and failures, of Roma migrants.

Dramatically, the outcome of the UK's Referendum vote in June 2016 to leave the European Union, and the ensuing uncertainty with regard to whether, how and when this might happen, added a completely new dimension of difficulty to the position of all EU nationals, including Roma people, living in the UK. A report by Marley Morris for the Institute for Public Policy Research concluded that:

> Following the UK's vote to leave the EU, Roma communities face a triple whammy of risks: uncertainty over their future legal status, rising concerns about hate crime, and a potential loss of EU funding for integration and support services (Morris, 2016: 26).

The Referendum decision immediately worsened the already precarious situation of Roma community members in the UK. The UK eventually left the EU in January 2020, with regulations governing the new relationship between the EU and the UK taking effect in January 2021 (Government of the Netherlands website, May 2021). The RSG (2021a, 2020) discuss the difficulties faced by Roma migrants in the UK, in relation to the European Union Settlement Scheme (EUSS) process. Additionally, this significant change took place at the time of the global pandemic caused by the novel SARS-CoV-2 virus, during which the situation of Roma people throughout Europe, including the UK, worsened as a result of '…a combination of health risks, economic deprivation and increased stigmatisation' (Walker, 2020: 1). In the context of the pandemic, Korunovska and Jovanovic (2020: 3) note that the extreme racism and poverty faced by Roma people in Europe has worsened during the past decade and that: 'In the richest continent on Earth, 80 percent of Roma surveyed live below their country's threshold for being at risk of poverty; about 30 percent live in housing without tap water, and every third Roma child lives in a household where someone went to bed hungry at least once in the previous month'. In the UK, the combined and ongoing negative effect on Roma health and well-bring of the Brexit outcome, together with the experience of the global pandemic, has added greatly to the already existing precarity and difficulty of Roma people's lives (RSG, 2021a, 2021b, 2020).

1.4 Research topic

Against the background described above, both historical and contemporary, the present study explored the experiences of members of Roma communities currently living in London, regarding their health and well-being, within a theoretical framework using post-structuralist concepts. The history of long-term prejudice and discrimination, seen to originate in the nomadic past of the Romani collectivity, and continuing throughout modern Europe, set the scene for the present study. The findings of the literature review (Chapter two) framed the present research in the context of health service limitations within the UK, as well as a programme of interventions designed to improve the quality of life of Roma people, including their health and well-being, in all EU Member States. The significant impact of socioeconomic factors, as well as of cultural factors, on the ability of members of Roma communities to access health and well-being services was also identified within the literature.

Using semi-structured individual interviews with Roma participants in three London boroughs, this contextual and explanatory qualitative study aimed to build a profile of the experiences of these participants in relation to health and well-being. A critical, thematic analysis approach was used to analyse the transcripts of the interview conversations (Braun and Clarke, 2006). The trustworthiness of the findings was supported by voluntary work, undertaken by the researcher with a charity supporting Roma people's mental health. Following the analysis of the interviews, the findings were problematised using concepts of voice, culture, identity, agency, and nomadism, through the lens of post-structuralist discussions and with a focus on different narratives and discourses regarding Roma health and well-being, as well as on Roma representation and Roma self-representation, in this context. The conclusions drawn from this discussion of the findings inform the recommendations made, to support best practice within health and well-being services for Roma community members in London and across the UK.

1.5 Research question and objectives

1.5.1 Research question

The study addressed the following core research question:

To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?

1.5.2 Specific objectives

1. To establish what is currently known about the health and well-being of Roma people living in the UK, and how Roma people's perspective has been represented in this context;
2. To explore the health and well-being experiences of Roma individuals in three London boroughs, and to identify specific themes impacting positively or negatively on their health and well-being, including barriers and facilitators;
3. To problematise the findings of the study, using the concepts of voice, culture, identity, agency and nomadism from a post-structuralist perspective.

1.6 Rationale

Roma community members were chosen as the subjects of this contextual and explanatory qualitative study as they occupy a unique place within modern Europe, experiencing, and continuing to experience, significant prejudice from majority populations since the sixteenth century (van Baar, 2011a; Acton, 2004; Hancock, 2002; Fraser, 1995). An extensive literature examining the health status of Roma community members in a range of countries across Central and Eastern Europe (Parekh and Rose, 2011; Zeman et al., 2003; Hajioff and McKee, 2000) suggests a wide range of difficulties, including significant barriers to accessing appropriate services.

Information currently available on the health and well-being of Roma migrant communities in the UK is limited, with many existing surveys drawing attention to the lack of research in this area (Warwick-Booth et al., 2017; European Public Health Alliance (EPHA), 2014; Lane et al., 2014; Ryder and Cemlyn, 2014; Training and Support 4 Services and Exiles (TS4SE) Co-operative Limited, 2009; Zeman et al., 2003; Hajioff and McKee, 2000). Many studies (Milan and Smith, 2019; Greenfields, 2012; Peters et al., 2009; Parry et al., 2004) focus largely on long-established UK Romani populations, and on Travellers of Celtic origin, and do not include Roma communities from Central and Eastern Europe.

Despite significant EU strategy intended to improve Roma health and well-being (van Baar, 2011a), policy and planning to meet the specific healthcare needs of Roma communities across the four nations of the UK has been limited and inconsistent, including the response to the requirements of the EU Framework for NRIS up to 2020 (Lane et al., 2014; Ryder and Cemlyn, 2014). A lack of monitoring by ethnicity has also resulted in a lack of data regarding the health and well-being of members of these groups within the UK (Women and Equalities Committee (WEC), 2019; Lane et al., 2014; Ryder and Cemlyn, 2014). The NRIS midterm review (European Commission, 2017) did not report any improvement in relation to Roma health and well-being in the UK. The midterm review described the generally slow improvement across the EU in all four key areas of the EU Framework for NRIS – education, employment, health and housing (European Commission, 2017). The review prioritised antidiscrimination measures, in order to generate the political will necessary to counter anti-Gypsyism, and to promote the success of Roma inclusion (ibid.). In relation to the Decade of Roma Inclusion, the need to involve members of marginalised groups in the process of setting goals for programmes designed to benefit their communities was also identified (Jovanovic, 2015). The report on the implementation of the NRIS (European Commission, 2019) noted vaccination campaigns and a facility for online reporting of hate crime in the UK. By the spring of 2021, the health aspect of the UK Gypsy, Roma and Traveller National Strategy had not been implemented (Ministry of Housing, Communities and Local Government and Lord Bourne, 2019).

As a result of the Romani people's lack of a self-written history and easily identifiable homeland, together with their experience of discrimination over many centuries (van Baar, 2011a; Hancock, 2002; Fraser, 1995), Romani self-representation within non-Romani society has been limited (Bhopal and Myers, 2008; Marsh and Strand, 2006; Belton, 2005; Acton, 2004; Hancock, 2002). Much of the story of the presumed Romani diaspora has been constructed by non-Romanies (Greenfields, 2013), and this has led to a plethora of non-Romani representations of 'Gypsies', Romanies and the Roma. Hancock (2002) and others have described the ways in which the Romani people have been both romanticised and vilified. In her previous work, whilst training education staff working with children from Romani groups, the present researcher encountered much uncertainty about the history, origins and language of this collectivity.

The present study seeks to address the issues described above by focusing on the health and well-being experiences of its Roma participants in London, using concepts derived from a post-structuralist perspective to problematise its empirical findings, in relation to the existing literature. The interacting impact of differing discourses within the National Health Service

(NHS), the voluntary sector, academia and Roma communities themselves regarding present-day interventions around Roma health and well-being was considered during the process of problematising the empirical data. Recommendations for the practical application of the findings in the UK healthcare context were developed from the experiences and understandings of Roma people themselves, interpreted using the concepts of voice, culture, identity, agency and nomadism, through a post-structuralist lens. The existing literature on Roma health and well-being in the UK largely concentrates on the impact of structural and cultural factors. The significance of discourse in constructing popular views of Roma people, and the resulting effects on all aspects of their lives, were largely ignored, with the exception of the report by Poole and Adamson (2008). However, Poole and Adamson (ibid.) do not state their theoretical or epistemological position. To the present researcher's knowledge, no other academic study has been conducted that concentrates specifically on Roma health and well-being experiences in several London boroughs, using a theoretical framework of post-structuralist concepts. The present study uses this theoretical perspective to offer ways of rethinking representations, and self-representations, of Roma people, in relation to health and well-being services in London and the wider UK.

At a time that saw the NHS in England under extreme financial pressure due to austerity measures, and levels of service provision for all across the UK under threat, this study provides a specific lens through which the health service experiences of members of this highly marginalised collectivity may be viewed. This research makes an original methodological and theoretical contribution to understanding the health and well-being experiences of Roma people in London, from which recommendations, in particular regarding the use of language in the healthcare context, are made.

1.7 Phases of the study

1. In order to meet objective 1, a critical literature review was conducted;
2. In order to meet objective 2, qualitative semi-structured in-depth interviews with individuals, self-identifying as Roma (n=19), in three London boroughs were undertaken. The data were analysed using a thematic analysis approach;
3. In order to meet objective 3, the findings of the study were problematised, using the concepts of voice, culture, identity, agency and nomadism from a post-structuralist perspective.

1.8 Scope and limitations

This is a contextual and explanatory qualitative study, looking at the health and well-being experiences of Roma adults in three London boroughs. Whilst many aspects of the context in which the experiences of the participants took place were shared by Roma people across the UK, the patterns identified and reported within the data cannot be taken to be definitive of the experiences of all Roma people in the UK, or even in London. There is significant heterogeneity within and among Roma communities (Hancock, 2002), and the findings of the present study are not generalisable beyond the experiences of some Roma people living in London. This is in keeping with the understanding that the outcomes of qualitative studies are not intended to be generalisable; rather, they should be seen as transferable (Shenton, 2004).

The present study focused on self-identified Roma individuals and did not include the health and well-being experiences of English or Welsh Romanies (Romanichals or Kale), or Travellers of Irish or Scottish heritage, all of whom have a much longer history of living in the UK (Fraser, 1995). Research into the health and well-being needs of members of these other groups has been undertaken elsewhere, and this often focuses on issues arising from accommodation policy linked to a current nomadic lifestyle (Milan and Smith, 2019; Greenfields, 2012; Parry et al., 2004).

An opportunistic sampling technique was used, where participants were identified through professional organisations working with Roma community members in three northeast London boroughs, and which provided the sampling frame for the study. The study was, therefore, focused on one London area, and did not aim to represent the experiences of Roma people across the whole of Greater London.

Individual interviews were conducted with a range of Roma adults across gender, age and country of origin. The views of children were not included. Participants were individuals who had established relationships with staff of the organisations approached and who had been in the UK for a number of years. The study did not include very newly arrived Roma people, whose experiences may have differed significantly. The health and well-being experiences of members of Roma communities in other European countries may also be significantly different.

A wide-ranging and open-ended interview schedule offered an opportunity to examine the experiences of the Roma participants within the chosen theoretical framework of the study, and to translate understandings of these experiences into recommendations for the practical application of the findings in the UK healthcare context. Additional understandings, gained by the researcher through voluntary work, enhanced the trustworthiness of the outcomes of the study (Ritchie et al., 2014).

Braun and Clarke (2006) discuss the active role of the researcher in the processes of developing the theoretical framework for a research study, in interpreting the data, and in reporting the findings. In keeping with the present study's theoretical framework, using concepts derived from a post-structuralist perspective, which places the contingency of meaning at its centre, this study offers one particular theoretical and methodological approach, and one interpretation of its findings, albeit within the wider field of understanding regarding the health and well-being of Roma people. Different approaches might offer equally credible outcomes. The research question, which sought to explore the health and well-being experiences of Roma people living in London, together with the outcomes of the literature review, and of the preliminary thematic analysis, led to the observation that issues regarding voice, culture, identity, agency and nomadism were emerging as significant. It was thought that these concepts would benefit from being problematised from a post-structuralist perspective, which is one that has not previously been used in relation to the health and well-being of Roma people in the UK.

LITERATURE REVIEW

2.1 Introduction

In order to examine current knowledge and understandings about the health and well-being of Roma people living in the UK, in relation to the proposed study, a critical literature review was carried out in several stages (Grant and Booth, 2009; Jesson and Lacey, 2006). The literature search set out to establish the scope and findings of previous research into the health and well-being experiences of Roma individuals and communities in the UK, to look at related policy and strategy and to critically appraise the methodologies and approaches used in previous studies. Relevant European reports and directives were included in the search. The search produced a wide range of documents relating to health and well-being issues among Roma communities in other European countries and among Gypsy and Traveller communities in the UK. Although there were clear similarities and cross-over between these three groups, the focus of the present study and of this literature review was on the health and well-being of Roma community members living in the UK.

The documents identified ranged from formal studies funded within the EU and by UK universities to small-scale surveys of uncertain methodology. Some of the more formal studies covered the EU as a whole, with the inclusion of chapters on the situation within the UK. Of the papers relating specifically to the UK, very few focused on Roma communities alone, with the majority being largely interested in the long-established English Romanichal Gypsy community and Irish Travellers. Among those papers that did refer to health issues affecting Roma communities living in the UK, this information was sometimes brief and usually locally based (Performance and Research Team, Sheffield City Council, 2015; Migration Yorkshire, 2012).

The initial papers examined indicated significant issues impacting on the health and well-being of Roma individuals and communities in the UK, and these key points were reinforced by further, systematic, reading of the literature. There was little evidence within these initial documents of robust academic research into the health and well-being needs of the Roma communities in the UK. As the research project proceeded, a number of additional or newly-published reports were identified, and were included in Chapter one or in the main analysis of the literature in Chapter two (WEC, 2019; Swanwick et al., 2018; Marsh, 2017; Newton and Smith, 2017; Smolinska-Poffley and Zawacki, 2017; Warwick-Booth et al., 2017;

Brown et al., 2016; Davis and Lovegrove, 2016; RSG, 2016; Smith and Newton, 2016; Willis, 2016; Grill, 2012; Department of Health, 2010). (See Appendix B for Literature Search Strategy.)

Three previous literature reviews of research into health issues within Roma communities were identified and examined (Parekh and Rose, 2011; Zeman et al., 2003; Hajioff and McKee, 2000). Parekh and Rose (2011: 139) focused on literature relating to '…the predominant Roma population that is living in segregated communities isolated from the majority population', in CEE countries. Both of the other reviews surveyed the picture worldwide, with Hajioff and McKee (2000) translating relevant papers and Zeman et al. (2003) dealing with literature available in full-text English. Hajioff and McKee identified four articles directly relating to the UK, with the majority of relevant articles being from Spain, the Czech Republic, Slovakia and Hungary, while Zeman et al. identified 18. However, in both cases, these UK studies focused almost entirely on long-established Gypsy populations, and on Travellers of Celtic origin, and did not include the more recently arrived Roma communities from Central and Eastern Europe. McKee (1997), cited in Hajioff and McKee (2000), however, mentioned the arrival in the UK of Roma families from Slovakia before the end of the Soviet Union, and noted the need for European governments to address health inequalities affecting neglected communities, including the Roma.

Nevertheless, these literature reviews offered crucial insight into the approach taken of most studies into the health and well-being of Roma community members more widely and the key issues raised and made suggestions for future academic work in the light of their findings. Despite the age of the reviews, many of the issues identified seemed to remain largely unchanged and these papers contextualised the urgency and complexity of the subject area. There appeared to be no published literature review focusing specifically on health and well-being experiences of Roma people in the UK.

Studies that looked at the health and well-being of Roma people living in the UK were closely analysed, with a focus on both the key findings and on the methodologies used (See Appendix C.) Analysis of the methodologies identified and the implications for the present study are included in the discussion section of this chapter (2.6). The literature as a whole was initially organised into fourteen topic areas, and the content of the documents in each of these areas was noted. Further consideration of these topic areas, together with an examination of the themes within the key studies, suggested three overarching and, to some degree, interacting themes: health service limitations; perception of a weak policy response; and social and cultural determinants of Roma health and well-being. An overview of the scope of the health and well-being issues affecting Roma people in the UK, as identified within the main literature search, is followed by an examination of the literature relating to each of these key themes. The discussion section of this chapter then presents a critical analysis of methodological considerations, relating to this literature on Roma health and well-being in the UK, and observations regarding the picture of research undertaken in this field at the time of the main literature search. This enabled identified gaps in the literature leading to the design of the present study to be outlined. Subsequently, a further review of literature relating to developments that occurred during the overall period of the study was undertaken. More recent literature was sought, regarding the health and well-being of Roma migrants in London and across the UK, focusing on post-migration experiences in the wider context of European as well as UK policy. Studies exploring the ongoing impact of the decision by the UK to leave the European Union and of the SARS-CoV-2 global pandemic were also sought. Both academic and generic literature were included in this search, with the key search terms being: ‘Roma health and well-being’, ‘Roma migrants UK’, ‘Roma migration UK’, ‘Roma post-migration UK’, ‘Roma marginalisation UK’, ‘Roma social exclusion UK’, ‘Roma voice’, ‘Roma and Brexit’, ‘Roma and EU settled status’, and ‘Roma and COVID-19’. This further literature update is presented in Section 2.7, with aspects being included throughout the text of the present study.

2.2 Overview of health and well-being issues

2.2.1 Focus on communicable disease and its threat to the majority population

A number of studies noted the significant focus on communicable disease and its perceived threat to majority populations, both worldwide and in the UK (Performance and Research Team, Sheffield City Council, 2015; European Commission, 2014a, 2014b; Zeman et al., 2003; Hajioff and McKee, 2000). Hajioff and McKee (2000) note that much of the literature ‘concentrates upon communicable disease or reproductive health. The limited evidence suggests increased morbidity from non-communicable disease, but there is little published on this topic’ (ibid: 864). They suggest that the existing research seems to ‘reflect views of the Roma as threats to the majority population, either through infectious disease or their contribution to the gene pool' (ibid: 866). It is necessary, however, to guard against assumptions and prejudice in relation to this aspect of healthcare and policy.

The European Commission (2014a: 7) report on the NRIS also notes this focus on communicable disease:

> Reports from several Member States show significant efforts in combating infectious diseases among Roma. While progress in this area is very much welcome, more attention on prevention and treatment of non-communicable diseases and on general health campaigns with a focus on the promotion of healthy lifestyles is also required. Furthermore successful measures remain to be systematized.

The paper produced by Sheffield City Council (Performance and Research Team, Sheffield City Council, 2015) listed a range of issues identified by health professionals within the Slovak Roma community, the largest group of Roma living in the city at the time. These included hepatitis A, B and C, tuberculosis and impetigo. Tuberculosis was identified by Tobi et al. (2010), amongst Roma participants in Barking and Dagenham, but not amongst Albanian/Kosovan, Lithuanian or Polish participants in their study. Willis (2016) notes the difficulties involved in producing accurate data regarding tuberculosis rates amongst Roma community members, due to the lack of coding for ethnicity, and screening for new arrivals that varies according to the prevalence rate of the disease in the whole population of the country of origin.

The National Institute for Health and Care Excellence (NICE) provides evidence-based recommendations for health and care in England. A search of the guidelines in September 2015 produced nine results for 'Gypsy Traveller' but only one result for 'Roma' (NICE guidelines, September 2015). Reflecting the concern reported by Hajioff and McKee (2000), regarding the perceived threat to host communities from communicable disease, this related to the inclusion of the Slovak Roma population in Sheffield in guidelines on service development for awareness-raising for people at increased risk of hepatitis B or C infection. A search of the guidelines in July 2016 produced eleven results for 'Gypsy Traveller' but only the same one result for 'Roma' (NICE guidelines, July 2016). By September 2017, this item had been removed with no indication as to the reason for this change (NICE guidelines, September 2017).

2.2.2 Prevalence of non-communicable disease

Several studies noted that, despite the focus on communicable disease in the literature on Roma health and well-being, non-communicable disease was, in fact, prevalent within Roma communities and warranted further research (RSG, 2015; Tobi et al., 2010; Zeman et al, 2003; Hajioff and McKee, 2000). The following were identified within the literature: a deficit in life expectancy; increased morbidity from non-communicable disease; coronary heart disease; cancer; diabetes; respiratory problems; asthma; smoking; obesity; untreated injuries; the impact of racism and discrimination on mental health; and high rates of anxiety, depression and self-destructive behaviour (for example, suicide and/or substance abuse). Many of the statements made about Roma people's health, however, appeared poorly substantiated, as explained below.

Hajioff and McKee (2000: 864) state that, 'Roma health is thought to lag behind that of majority populations, with some studies suggesting a fourfold increase in infant mortality and a 10-year deficit in life expectancy but research on the health of the Roma is limited and difficult to access'. Ten years later, echoing the speculations of Hajioff and McKee in 2000, participants in the study by Tobi et al. (2010) noted that many community members died young. In 2011, the European Commission (2011: 3) reported that, 'Life expectancy at birth in the EU is 76 for men and 82 for women. For Roma, it is estimated to be 10 years less'.

Tracing the source of the 10-year deficit in life expectancy claim is interesting. Hajioff and McKee (2000) cite McKee (1997), who cites Braham (1993). Braham's report was written for the United Nations High Commissioner for Refugees (UNHCR), at a time when Roma people were increasingly under attack in Central and Eastern Europe. Braham (1993) collected information about the lives of Roma people in Romania, Hungary, the Czech and Slovak Republics and Poland, and Roma asylum seekers in Germany, using literature searches and field surveys.

In Prague, at the Romany Association of Children and Youth, Braham was told, 'They die about ten years earlier than we do. In some areas infant mortality is like in a third world country. *But there are no statistics*' (ibid: 69, italics added). From Romania, Braham reports, 'Longevity is fifteen to twenty years shorter than normal, averaging between fifty and fifty-five years' (ibid: 19), but the origin of these figures is not specified. In contrast, in Poland, Andrzej Mirga, an ethnologist from the University of Kraków, '…said that there are many older people among the Roma, suggesting a life-span closer to that of the Polish population itself' (ibid: 93).

The European Commission (2011), in making the ten-year deficit claim, cites other European Commission and EU documents, without clearly identifying the original source of this statement. The 10-year deficit in life expectancy and the fourfold increase in infant mortality have almost become catchphrases within the literature on Roma health but should be regarded with considerable caution in terms of their factual status, and of their transferability between geographical and temporal settings. Nevertheless, the serious nature of these claims indicates a need for focused research and appropriate intervention.

Several of the published studies identified specific difficulties faced by Roma communities in the UK, regarding their health status and well-being (Performance and Research Team, Sheffield City Council, 2015; Greenfields, 2012; Migration Yorkshire, 2012; RSG, 2012; TS4SE Co-operative Limited, 2009). The lack of consistent national data on the health status of Roma communities appears to have produced a situation where the studies that do exist are either specifically focused on one geographical area (Performance and Research Team, Sheffield City Council, 2015; Migration Yorkshire, 2012), or are more general overviews, combining direct programmes of work with anecdotal evidence and reference to other studies (Greenfields, 2012).

For example, Migration Yorkshire (2012: 5) produced a guide to good practice in which they suggested that local research and anecdotal information from health practitioners within the region highlighted a range of health concerns resulting from ‘generations of discrimination, poor living conditions and exclusion from services’. A range of health concerns among recently arrived Roma communities in the region were identified, including diabetes, coronary artery disease, obesity, teenage pregnancy and nutritional deficiencies (ibid.). The Sheffield City Council (Performance and Research Team, Sheffield City Council, 2015) report identified diabetes mellitus, coronary heart disease, obesity, teenage pregnancy, nutritional deficiencies, neonatal health issues relating to consanguinity, childhood anaemia and cultural issues relating to healthcare and homeopathy among health issues within the Slovak Roma community in Sheffield.

Among the Roma participants in the fieldwork of the Barking and Dagenham study, 54% rated their overall health status positively, which was higher than ratings given by Lithuanian and Albanian/Kosovan participants. Within the study, Roma people aged from 16 to 76 years had the highest rates of smoking, at 74% (Tobi et al., 2010). Among the key health issues for Roma people identified through the fieldwork of this study were diabetes, asthma, cancer and heart problems (ibid.).

2.2.3 Children’s and young people’s health and well-being

Child health issues made up a significant aspect of the documents examined through the literature review. Again, however, caution is required regarding the empirical evidence for claims regarding the health and well-being of Roma children and young people. The voices and views of children and young people themselves were absent from the literature, apart from a study in Wales, which included '…some input from younger children', but the number of Roma participants in this study was not specified (Marsh, 2017).

In 2013, the Parliamentary Assembly of the Council of Europe adopted a Resolution on ending discrimination against Roma children, focusing on interventions in early childhood, including maternal and child health, as well as on improved access to inclusive and quality education (European Commission, 2014b). The report by Migration Yorkshire (2012) refers to European Commission data regarding increased child mortality rates among Roma. In 2011, the European Commission wrote:

> A United Nations Development Programme report on five countries noted that Roma child mortality rates are 2 to 6 times higher than those for the general population, depending on the country. High levels of infant mortality among the Roma community are reported in other countries (European Commission, 2011).

The European Commission (2014b) reports that vaccination uptake among Roma is not consistent across member states. Anecdotal findings suggest comparatively low levels of vaccination rates in the EU countries with the highest levels of migrant Roma, including the UK.

A wide range of child health issues among Roma communities in the UK were identified within the literature (Fekete, 2015; Performance and Research Team, Sheffield City Council, 2015; European Commission, 2014b; Migration Yorkshire, 2012; Tobi et al., 2010; European Commission, 2011; TS4SE Co-operative Limited, 2009). These included: an increase in infant and child mortality rates, poor vaccination uptake, tuberculosis in children, meningitis, disability, hearing loss, neonatal health issues relating to consanguinity, childhood anaemia, impetigo, nutritional deficiencies, vitamin deficiencies, malnutrition, dystrophy, rickets, and teenage pregnancy. Of the papers identified by Hajioff and McKee (2000), the largest number related to child health, including congenital anomalies. However, this study did not include any evidence regarding Roma child health issues in the UK.

Teenage pregnancy was noted by Migration Yorkshire (2012) as a health concern affecting local Roma communities. Teenage pregnancy was also noted in the Sheffield report, within the local Slovak Roma community (Performance and Research Team, Sheffield City

Council, 2015). Willis (2016) describes the analysis of teenage pregnancies in Sheffield in 2014. She notes that, whilst 21 of 32 reported conceptions among girls under seventeen were those of Roma girls, this was 8% of the total of 253 pregnancies reported: 'These data suggest that pregnancies among Roma girls under 18 form a fraction of the total teenage pregnancies for Sheffield as a whole' (ibid: 40). Willis also notes that some Roma parents are now prioritising education over starting a family early, as opportunities for relatively well-paid work are available for their daughters in the UK (ibid.).

The Sheffield profile also reported evidence of hearing loss as an issue amongst Roma children. Sheffield Council's Service for Deaf and Hearing Impaired Children reported 7% of all Roma school-aged children as having significant hearing loss (Performance and Research Team, Sheffield City Council, 2015). Willis (2016) reports that bilateral sensory neural hearing loss among Slovak Roma children in Sheffield is approximately twenty times greater than that of the general population. She states that '[o]ne third of the current caseload of 280 children at the SCH (Sheffield Children's Hospital) receiving ongoing care for hearing loss is made up of Roma children' (ibid: 43). This trend was confirmed across the whole of England in the study by Swanwick et al. (2018), who also found significant under reporting, due to the reluctance of Roma families to self-ascribe. They note: 'Through our examination of the relationship between being deaf and being Roma we also identify overlapping areas of precarity that have serious implications at an individual level for childhood development, education and achievement, as well as for longer term health and well-being' (ibid: 3).

2.3 Health Service limitations

The ongoing funding crisis within the NHS across the UK, and the resultant pressure on services, provided the background to the health and well-being experiences of Roma people living in the UK (The Social Marketing Gateway, 2013; European Union Agency for Fundamental Rights (FRA), 2012; Poole and Adamson, 2008). A wide range of health and well-being needs were identified within the literature. A certain focus on communicable disease was evident, although many other health and well-being issues were also present. Despite this, significant barriers to accessing services were identified. Fundamental to a perceived lack of attention to the needs of Roma people was the absence of monitoring by ethnicity, which could provide the health services with information on which to build improvement. The fact that successful strategies for improving access were also identified and initiated, largely by the voluntary sector, is indicative of the possibilities for achieving the changes required by the European programmes.

Issues of responsibility were raised within the literature (The Social Marketing Gateway, 2013; Wright, 2011; Poole and Adamson, 2008). The Social Marketing Gateway (2013) noted the EU requirement for Member States to take primary responsibility for improving the situation of marginalised populations, and that this should be addressed at the local level. Although a wide range of health issues among Roma people were identified by practitioners (Willis, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2015; Tobi et al., 2010; Zeman et al, 2003; Hajioff and McKee, 2000), Poole and Adamson (2008) reported Roma patients being seen as a burden by healthcare professionals and a perception among staff of wasted resources when appointments were not kept, with an associated threat to public immunisation programmes. Prior to January 2014, transitional restrictions on citizens of Bulgaria and Romania led to uncertainty among healthcare professionals regarding their level of responsibility (Wright, 2011; Poole and Adamson, 2008), and a sense of limited entitlement for Roma people may have persisted beyond this date. Nevertheless, a perception on the part of Roma patients of inadequate services (FRA, 2012; Fremlová, 2009; Fremlová and Ureche, 2009) sometimes resulted from a lack of knowledge due to differing healthcare systems in countries of origin and the UK (Brown et al., 2016; Poole and Adamson, 2008) and, in some cases, UK services were positively experienced, due to a perceived lack of discrimination (Fremlová, 2009; Fremlová and Ureche, 2009).

Key areas identified in this summary of health service limitations are examined in greater detail in the following sections.

2.3.1 Barriers to accessing services

A wide range of interrelating barriers to accessing healthcare services were identified within the literature, reflecting both the structural and the cultural factors considered below (2.5). These fell into four main categories: cultural factors preventing Roma individuals from seeking healthcare services (Marsh, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016, 2015, The Social Marketing Gateway, 2013; FRA, 2012; RSG, 2012; Tobi et al., 2010; Poole and Adamson, 2008; Zeman et al, 2003; Hajioff and McKee, 2000), prejudice and discrimination (Smolinska-Poffley and Zawacki, 2017; RSG, 2016, 2015; EPHA, 2014; Lane et al. 2014; Greenfields, 2012; RSG, 2012; Tobi et al., 2010; Zeman et al, 2003), practical difficulties in accessing health and well-being services (Marsh, 2017; RSG, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2015; Lane et al., 2014; Wright, 2011; Tobi et al., 2010) and language and communication difficulties (National Roma Network, 2017; Warwick-Booth et al., 2017; Brown et al., 2016; Willis, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2016, 2015; McNulty, 2014; Wright, 2011; Tobi et al., 2010; Fremlová, 2009; Fremlová and Ureche, 2009; Poole and Adamson, 2008).

Lane et al. (2014) highlight a lack of familiarity with the NHS, and language barriers, as contributing to difficulties for Roma people in accessing health services, or communicating concerns about their health, and suggest that the attitudes of some healthcare staff could make access to health services difficult. Whilst pointing out the negative impact for Gypsies and Travellers of a nomadic lifestyle on health outcomes, Lane et al. do not discuss the implications of high levels of mobility within housing among the Roma communities for consistent healthcare provision. On a more positive note, one participant notes that Roma are now able to register with a General Practitioner (GP) (ibid.).

Tobi et al. (2010) quote a Roma community member who stressed the difficulty experienced in not having an interpreter when visiting a GP and this issue was endorsed by other Roma participants. The lack of interpreting services when visiting a GP emerged as a crucial difficulty for Roma individuals and led to them using accident and emergency departments on a regular basis, where they experienced a more supportive environment, although often their health need did not really constitute an emergency. Difficulties with communication were noted to have a reinforcing effect on a lack of cultural understanding between members of Black and minority ethnic (BME) communities and NHS staff. Another interviewee spoke of the difficulty Roma community members had in understanding letters received regarding medical issues. A further difficulty was a lack of information about available healthcare services, including mental health services and services for disabled people. One Roma participant stated, ‘Many Roma have problems with reading so it would be good [if] we could find in GP practices and other public places simple comprehensive information, leaflets in community languages’ (ibid: 22).

Difficulties were also raised regarding registering with doctors’ surgeries when living in the houses of friends and relatives and, when health services were accessed, long waits were reported across the range of appointments, specialists, referrals and test results. Fifty-seven percent of Roma adults interviewed had registered with a GP (ibid.). Sheffield City Council (Performance and Research Team, Sheffield City Council, 2015) reported that practitioners had identified a lack of health education and promotion for the Slovak Roma community, high use of accident and emergency departments, thought to often be unnecessary, the UK appointment-based system to be a barrier to access, and a lack of availability of translation services. More positively, however, Brown et al. (2016) noted that some Roma participants spoke highly of healthcare services received in the UK, often in contrast to their experiences in their countries of origin. In 2020, during the SARS-CoV-2 global pandemic, Public Health England produced a new document promoting immunisation against influenza in the Romani language (Public Health England, July 2020). It was unclear as to which version of Romanes (the Romani language) had been used, or how Roma speakers of Romanes might access this information. Nevertheless, this was a rare example of a direct approach by the UK health services towards members of Roma communities, even if it took the emergency circumstances of a pandemic for this to happen.

2.3.2 Strategies for promoting improved access to services

Despite the barriers to access of healthcare services described above, strategies for promoting improved access were also identified within the literature (Marsh, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2015; European Commission, 2014a; EPHA, 2014; Migration Yorkshire, 2012; RSG, 2012; 2010; Council of the European Union, 2009). Recommendations included: further research into the health needs of Roma communities; research to explore the impact of racism and discrimination on the mental health of the Roma; improved ethnic monitoring; increased awareness by policy-makers of the specific health needs of Roma communities and incorporation of these into health strategies; recognition of the wider determinants of health; recognition of general health and lifestyle issues; recognition of issues of access to both primary and secondary care; and locally sensitive support strategies.

There appeared to be a need for training and education for both healthcare professionals and members of Roma communities. The importance of culturally specific targeted training for healthcare professionals, including an understanding of discrimination faced by Roma people, was stressed within a number of studies (Shallice and Greason, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2015; Equality Commission for Northern Ireland, 2014; FRA, 2012; Wright, 2011). Notwithstanding the observation of Acton et al. (1997) discussed below (2.5.3), providing education for Roma people about systems within the NHS, and related understandings of health and well-being, were also seen as important (Performance and Research Team, Sheffield City Council, 2015; The Social Marketing Gateway, 2013; RSG, 2012).

The good practice guide produced by Migration Yorkshire (2012) describes four examples of successful initiatives supporting the health of Roma people in Sheffield, Leeds, the London Borough of Newham and Valencia in Spain. They identify five key elements in providing good healthcare practice when working with Roma communities: '[a]ctive participation of Roma people; involvement of the voluntary sector; …ensuring mainstream health services are appropriate to the needs of Roma people; awareness of the gender dimension [when working with Roma patients]; and involvement of regional and local authorities [in supporting and including Roma communities]' (ibid: 11). They point out that these reflect the Council of the European Union Conclusions on the Inclusion of Roma (Council of the European Union, 2009).

The Roma Support Group's (2012) groundbreaking 'Roma Mental Health Advocacy Project' involved a range of partners, mainly within London. They recommended a model of work focusing on: '[i]mproving communication strategies with Roma mental health service users; person-centred care; [a] holistic approach that combines individual and social empowerment; [a] holistic approach that supports individuals to improve other aspects of their lives that [affect] mental health such as housing, welfare etc.; and [r]esearch to explore the impact of racism and discrimination on the mental health of the Roma' (ibid: 7). The evaluation report (ibid.) describes its initial phase, which ran between 2008 and 2011, and focused on engaging the client group and signposting clients to appropriate services. The commitment of the staff to exploring and addressing very difficult and sensitive issues, in a genuine partnership with their Roma clients, shines through the report and the project continues to develop to this day. Two more recent reports describe the progress of the project, through a programme of training for local healthcare professionals, in partnership with Newham Clinical Commissioning Group (CCG) (Smolinska-Poffley and Zawacki, 2017; RSG, 2015).

Taking a European-wide view, the report of the EPHA (2014) suggests the use of medical caravans targeting the poor/Roma, and the need to secure sustainability of employment of Roma Health Mediators. The European Commission (2014a: 54) 'Report on the implementation of the EU framework for National Roma Integration Strategies' advises the UK that, 'Initiatives targeting the needs of newly arrived Roma communities should be continued' and 'Monitoring the impact of mainstream measures and activities undertaken on Roma should be considered'.

2.3.3 Absence of monitoring by ethnicity

Across the UK there has been no monitoring by ethnicity of Roma individuals within the health services, which was reflected in the fact that existing web-based NICE guidelines for England gave very little recognition to Roma people as a distinct group, although there were several items giving guidelines around the health of Gypsies and Travellers (NICE guidelines, September 2017, July 2016, September 2015).

A key difficulty noted by several studies (Fekete, 2015; Lane et al., 2014; European Commission, 2014a; Mathur et al., 2013; Ryder and Cemlyn, 2014) was the use by the National Health Service in England and Wales of the sixteen ethnic minority categories from the 2001 Census, which failed to include any reference to Roma, or to other groups of Gypsies and Travellers. Lane et al. (2014) pointed out that, although NHS Scotland had adopted the 2011 Census Classification and, therefore, collected data on Gypsies and Travellers, this did not include Roma. Along with Ryder and Cemlyn (2014), Lane et al. (2014) also recommended a Dataset Change Notice mandating the use of the 2011 Census Ethnic Group classification, with the addition of Roma people. However, these recommendations have apparently not been adopted, with the NHS Data Model and Dictionary (March 2021 release) retaining the 2001 Census categories.

Monitoring by ethnicity has, itself, been critiqued, both in terms of its practicalities and, also, in terms of its racialising outcomes, if not intent (Acton et al., 2016; Gheorghe, 1997; Kohn, 1996). Where ethnic monitoring categories do exist for Roma individuals, as, for example, in education in England (United Kingdom Government website, May 2021), fear of discrimination can lead to avoidance of identification under such a category (Acton et al., 2016). However, without this, Roma people, along with other Gypsies and Travellers, are grouped alongside homeless people, asylum seekers and people who misuse substances (NICE guidelines, November 2018). This anomalous positioning is strangely reminiscent of the sixteenth century defining of Roma as vagrants, and their claims of an ethnic identity and language being ignored (Acton, 2004). Ironically, in terms of barriers to accessing services, one of the issues most frequently cited in the literature related to language and communication difficulties (National Roma Network, 2017; Warwick-Booth et al., 2017; Brown et al., 2016; Willis, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2016, 2015; McNulty, 2014; Wright, 2011; Tobi et al., 2010; Fremlová, 2009; Fremlová and Ureche, 2009; Poole and Adamson, 2008).

The National Inclusion Health programme for England was put in place by the Department of Health (2010). Under this initiative, 'gypsy, Roma travellers' appeared within a long list of socially excluded groups, alongside 'migrant workers', 'asylum seekers and refugees', 'ethnic or religious minorities' and 'non-English speaking linguistic minorities' (ibid: 10). The list also included, among others, 'those with no recourse to public funds', 'sex workers', the 'long-term unemployed' and 'offenders and ex-offenders' (ibid: 10). By 2016, a report on education and training for health professionals, in relation to Inclusion Health, addressed the needs of five categories of '…vulnerable people who are either homeless, Gypsies and Travellers, Roma, sex workers and vulnerable migrants' (Davis and Lovegrove, 2016: iv). The earlier focus on migrancy remained but other immigrant communities appeared to have largely regained a recognition of their ethnicities. These authors noted that, '…for the study Roma should be considered as a separate vulnerable group as there is less evidence concerning this community' (ibid: viii). Roma people, in this case, are separated from those more likely to be currently nomadic, but they remain also separated from other immigrant communities. The categorisation of Roma people appears to have more to do with migrancy than with immigration, and we are reminded again of the hostility towards 'vagrants' experienced by Romani people in Western Europe in the sixteenth century (Acton, 2004).

The erratic nature of UK data collection regarding Roma people is further illustrated by guidelines issued by the Office for National Statistics (ONS) (May 2015), aiming to harmonise data collection by ethnicity within the UK. The ONS (ibid: 20) states:

> There are differences in data collection across the UK for 'Gypsy, Traveller or Irish Traveller', which make it difficult to produce a UK estimate. Gypsy, Traveller or Irish Traveller is collected in England and Wales and 'Gypsy/Traveller' is collected in Scotland and they are both output [subsumed] under 'White'. However, if there is a need to show a UK output for, 'Gypsy, Traveller or Irish Traveller' (and the numbers are not small or disclosive,) the responses from the GB questions can be combined with the responses from the 'Irish Traveller' category from Northern Ireland. It is recommended that 'Roma' responses are included under 'Other ethnic group' and a footnote should be presented to clarify this. However for Scotland it is likely that some 'Roma' might be included under Gypsy/Traveller. Northern Ireland's framework for monitoring minority ethnic and migrant people, published by the Office of the First Minister and deputy First Minister in July 2011 recommends that Roma is categorised under 'Other' ethnic group.

> This is because there is a distinct category for Irish Travellers, who by law (Race Relations Order) are categorised as an ethnic group in their own right. Roma is not a subset of the Irish Traveller group and the need is to have accurate data on both Roma and on Irish Travellers.

A study by the Irish Traveller Movement in Britain (ITMB) (2012) of ethnic monitoring of Gypsies and Travellers by NHS trusts in England found that 71% of respondents conducted no ethnic monitoring of these groups. The rationale in most cases was that it was not a requirement, despite the serious health inequalities experienced by members of these communities (ibid.). Amongst its recommendations, the ITMB (ibid: 14) also suggested that '[t]he DH [Department for Health] should issue a national "data change notice" to include Gypsies, Roma and Travellers alongside the 16+1 other ethnic categories which are monitored by the NHS. This would bring the NHS in line with Gypsy and Traveller inclusion in the 2011 census'.

A later example showed that the marginalised positioning of Roma people remained relatively unchanged. In August 2019, the present researcher attended an event in London, held by Friends, Families and Travellers (FFT), looking at health inequalities faced by members of Gypsy, Roma and Traveller communities in England. The keynote speaker, from the Department for Health and Social Care, outlined preliminary work being undertaken at the time to develop the health aspect of the UK Gypsy, Roma and Traveller National Strategy, due to commence in the spring of 2020 (Ministry of Housing, Communities and Local Government and Lord Bourne, 2019). This work was located under the Health Inequalities Team. A wider team was reported to be working on child health, violence, rough sleeping, Gypsy, Roma and Traveller communities, and other vulnerable groups who had no policy, including sex workers, the homeless and vulnerable migrants. There was to be a strong focus on raising awareness, tackling barriers, and prevention. Subsequently, funding for extra education support for Gypsy, Roma and Traveller children and young people was announced (Ministry of Housing, Communities and Local Government and Lord Greenhalgh, 2020), although further information regarding promised funding for projects in the areas of health and integration did not appear to be available in early 2021 (Ministry of Housing, Communities and Local Government and Lord Bourne, 2019).

In the same year, the Women and Equalities Committee (2019: 40) stated: 'As our inquiry progressed, it became clear that, while Roma people experienced some of the same inequalities as Gypsies and Travellers, many of the issues that were brought to us had more in common with other migrant groups and some were unique to Roma communities living in the UK'. This key report (ibid.) on tackling inequalities faced by Gypsy, Roma and Traveller communities in the UK noted the inclusion of Roma people, until 2020, in some of the 22 government-run pilot projects, focusing on migrant groups, under the Controlling Migration Fund (Ministry of Housing, Communities and Local Government, 2018). Although members of Roma communities may have benefitted from aspects of these projects, here, again, they are constructed as presenting a problem and the very name of the programme carries stigmatising and punitive undertones (WEC, 2019). Ruz (2015) considers the negative connotations carried by the term 'migrant', which is often used in relation to Roma people, as well as the use of the word 'immigrant', when the movements of people from non-western countries are being discussed.

The ongoing marginalising of Roma people in the UK echoed their positioning within the National Inclusion Health programme for England (Department of Health, 2010), and within the NICE guidelines (November 2018), where Gypsy, Traveller and Roma people appeared as part of a collectivity of marginalised communities, under the category of 'Underserved groups', regarding difficulties in accessing healthcare services or appointments, but with no evidence or advice about their health and well-being needs specifically (ibid.).

In early 2021, in the context of the global health pandemic generated by SARS-CoV-2, advice from the Joint Committee on Vaccination and Immunisation (JCVI) on the vaccination programme schedule included a focus on mitigating health inequalities, in relation to increased risk from COVID-19 (Department of Health & Social Care, 2021). Annex A to this document (Campos-Matos and Mandal, 2021: 6) noted that, '[p]rotected characteristics, such as ethnicity and sex, as outlined in The Equality Act (2010) …, provide an actionable framework to target those who frequently suffer worse health outcomes'. Nevertheless, and despite the legal recognition of ethnicity of all Gypsy, Roma and Traveller community members, the needs of these groups are addressed under the category of social exclusion, along with '…homeless people, …people in contact with the justice system, vulnerable migrants and sex workers…' (ibid: 6), rather than within the broad category of Black, Asian and minority ethnic (BAME) groups. In addition, this annex returns Roma people to the Gypsy, Roma and Traveller grouping, in contrast to the Inclusion Health training document (Davis and Lovegrove, 2016), which suggested that the needs of the Roma differed from those of Gypsies and Travellers and should be considered separately, and to the observations of the Women and Equalities Committee (2019). Eventually, some progress was seen to have been made when a category for Roma people was included within the 2021 UK Census (WEC, 2019).

2.4 Perception of a weak policy response

A weak UK government response to the European requirement for an NRIS, which is intended to include health, was reflected in a lack of progress in the area of Roma health and well-being (National Roma Network, 2017), a call for research into the health and well-being needs of Roma people in the UK (Shallice and Greason, 2017; Warwick-Booth et al., 2017; RSG, 2012; Fremlová, 2009), and a need for coherent national, regional and local policy (National Roma Network, 2017; Willis, 2016; Clark, 2014; Migration Yorkshire, 2012; Fremlová, 2009; Fremlová and Ureche, 2009). There was a disjunction between EU policy recommendations and experience at a local level (Migration Yorkshire, 2012), with Poole and Adamson (2008) noting the need for political solutions. The midterm review of the EU Framework for NRIS (European Commission, 2017), and submissions made to the Women and Equalities Select Committee (National Roma Network, 2017; Shallice and Greason, 2017), highlighted the lack of progress and suggested a strong lack of political will to address the health and well-being needs of Roma people in the UK. These areas are examined in the following sections.

2.4.1 Poor response by the UK to requirements of the EU Framework for National Roma Integration Strategies

The findings of the main literature review located the position of the UK Roma population and that of the present study within a comprehensive framework of European Union reports and directives. Nevertheless, it was clear that the absence of monitoring of the health status of Roma people, underpinned by a lack of political will, resulted in the virtual absence of strategic policy regarding Roma health throughout the UK.

Despite ‘The Strasbourg Declaration on Roma’ in October 2010, the efforts of the European Decade of Roma Inclusion (2005 – 2015), leading to the adoption in 2011 of ‘An EU Framework for National Roma Integration Strategies up to 2020’, and significant EU funding to support Roma inclusion, progress across Europe and in the UK has been slow. ‘The Strasbourg Declaration on Roma’ was a Council of Europe (2010) document, recognising the social and economic marginalisation of Roma in many parts of Europe and noting that existing European legislation and protocols should underpin an effective programme of inclusion and the protection of the human rights of the Roma in Europe. The declaration prioritised three main areas: non-discrimination and citizenship, social inclusion, and international cooperation. Under the section on social inclusion, the document states, 'Health Care (35) Ensure equal access of all Roma to the healthcare system, for instance, by using health mediators and providing training for existing facilitators.' (ibid: 3).

The European Decade of Roma Inclusion (2005 – 2015) sought to address the significant gaps between Roma community members and other citizens in a group of twelve European countries (eleven in Central and Eastern Europe, plus Spain) (Roma Integration 2020 website, 2017). This initiative was funded by the OSF and the World Bank (ibid.). Despite the hopes for the initiative, overall outcomes in these countries were very limited. Jovanovic (2015: 1) states, '...all in all, the daily life of Roma remains a struggle no other ethnic group in Europe faces'.

The European Commission's (2011) 'An EU Framework for National Roma Integration Strategies (NRIS) up to 2020' called on all EU Member States to prepare a strategy to address Roma inclusion in the same four areas identified for the Decade of Roma Inclusion: education, employment, health and housing (ibid.). Jovanovic (2015) writes that the reason for the creation of the NRIS programme was to attempt to place responsibility for the situation of Roma domestically on every EU member government. However, he notes that, particularly in Western Europe, governments sought to retain political popularity through taking a hardline approach to Roma at home while, at the same time, being seen to support Roma inclusion policy on the wider EU stage (ibid.). A significant presence within the literature was that of reports and critiques relating to the UK's late response in 2012 to the EU request for an NRIS from each of its Member States (Fekete, 2015; European Commission, 2014a; European Commission, 2014b; Lane et al., 2014; Ryder and Cemlyn, 2014; Willers and Greenhall, 2012).

Ryder and Cemlyn (2014: 27) noted that, 'with the development of the localism agenda, English local authorities now have the major responsibilities for the integration of Gypsy, Irish Traveller and Roma populations; yet, as there are no targets or monitoring mechanisms, it is difficult to see how the integration of Gypsy, Irish Traveller and Roma will be achieved or evidenced'. Among their recommendations under the health strand of the framework, Ryder and Cemlyn recommended that the UK government should mandate the use of the 2011 Census ethnic group classification and should include Roma people. In addition, they recommended a national Gypsy, Traveller and Roma health survey, to ascertain the health status and needs of these communities (ibid.). Lane et al. (2014: 5) stated that, ‘It is… critical that local Gypsy, Traveller and Roma health assessments are conducted and that these communities are fully involved in this process.’

A paper published by the Institute of Race Relations (Fekete, 2015: 1) states that ‘[t]he European Commission (EC) gave the UK government an “overall poor rating” for the progress report it delivered in 2012 on its Roma integration strategy.’ Fekete asked what the [UK] government was doing ‘to respond to EC criticisms of its failure to set up proper mechanisms to monitor Roma integration’ (ibid: 1).

Willers and Greenhall (2012: 2) noted that, although the EU requirement was for Member States’ NRIS to be designed ‘in close cooperation and continuous dialogue’ with Roma NGOs and other stakeholders, in the UK very little genuine consultation took place. The UK took advantage of the fact that the EU offered Member States the opportunity to develop or update policy documents relating to broad social inclusion policies, rather than producing a specific NRIS. In addition, the UK Government’s Ministerial Working Group (MWG) focused on the needs of Romanichal Gypsies and Irish Travellers, including the needs of Roma only where they overlapped with those of these other groups. The one area in which relevant policy existed was in education. Willers and Greenhall (ibid: 3) stated:

> The MWG’s decision not to address the disadvantages experienced by [the Roma] in our society, save where they coincide with those experienced by Gypsies and Travellers seems to be wholly contrary to both the spirit and the letter of the Framework and to defy logic.

With regard to health, the European Commission (2014a) described the key steps undertaken within the UK since 2011, which are extremely scant. In Northern Ireland, these focused on proposals for improving Traveller health and well-being and, in Wales, on the revision of health and homelessness standards and on plans to publish guidance for healthcare providers. There was also a general reference to a Welsh Roma health project, health mediators and a regional minority ethnic health and well-being steering group. The single UK initiative identified, specifically targeting Roma communities, related to plans in Yorkshire for supporting access to the national health services for newly arrived Roma communities, with support from Roma women health mediators.

2.4.2 Inadequate and inconsistent approach across the UK

Across the UK, responsibility for NHS services now rests with the devolved governments of each of the member countries. Alongside the absence of health data on Roma individuals and communities across the four nations of the UK, none of the countries has a structured governmental approach (European Commission, 2014a). Consequently, intervention and support for the health and well-being of Roma community members appears patchy and inconsistent, and dependent upon local services and NGOs in areas with significant Roma populations. Within the literature, a small number of Scottish studies were identified (Clark, 2014; The Social Marketing Gateway, 2013; Poole and Adamson, 2008) as well as the study in Wales (Marsh, 2017), which give some insight into the situation of Roma people living in these countries in the area of health and well-being.

The three Scottish reports focused largely on Glasgow, with Poole and Adamson (2008: 14) offering recommendations '...relating to the future planning, commissioning and development of services'. Frontline service providers working with Roma in Govanhill, Glasgow, were interviewed. Interviews were not conducted with Roma clients, themselves, due to perceived language barriers and the lack of trusting relationships between the researchers and potential Roma participants. Language and cultural issues were identified as the main barriers to Roma people accessing GP and other health services (ibid.).

Clark (2014: 6) notes the parallels between '...William Beveridge's 'five giants'... '*want, disease, ignorance, squalor and idleness*' (Beveridge, 1942)' and current areas of social policy as applied to the Roma. In relation to Health/'Disease', he states: 'There is some evidence of poor health amongst the [Roma] community with low GP registrations, immunisation take-up and mental health issues. However, there have also been reports of good access and treatment at some GPs [sic] practices and word quickly spreads when a practice is seen as being 'good' with Roma patients within the communities' (ibid: 6).

The 2013 report 'Mapping the Roma Community in Scotland' (The Social Marketing Gateway, 2013: 3) states its aim as, '... to ensure that the European Commission's Roma inclusion objectives are applied in Scotland and that the Scottish Government has a robust evidence base'. With regard to Roma communities in Scotland, the report notes the familiar key challenges in education, employment, housing and healthcare. It notes that negative media coverage influences public opinion but, also, that the poverty that many Roma individuals are caught in leads to underground activities and, sometimes, criminality. It is noted that overcrowding is tolerated, as conditions are better than those left behind in the countries from which the Roma have come (ibid.).

The report states that, in 2013, there were approximately 4,000 – 5,000 Roma living in Scotland, with the vast majority in the Govanhill area of Glasgow. It notes the better integration of smaller numbers of Roma living in Fife (ibid.). Regarding healthcare specifically, the report identifies a strain on healthcare providers in areas with Roma communities and Romanian Roma are reported as sometimes returning to Romania to access healthcare treatment. Untreated diabetes and heart disease, as well as obesity and alcohol use are identified among the Roma (ibid.). The report also notes increasing confidence among settled Slovak Roma to use GP services, and the importance of improving access as the first step towards improving healthcare for Roma community members (ibid.).

The report by Marsh (2017) documents a project led by the Romani Cultural & Arts Company (RCAC) with the support of Public Health Wales and the NHS Centre for Equality and Human Rights. Participants in this study included Slovak Roma community members in Newport, but the number of Roma participants was not specified, making it difficult to know which of its findings relate directly to the experiences of Roma people living in Wales.

Information regarding the health and well-being of Roma people in Northern Ireland was sparse. However, the Equality Commission for Northern Ireland (2014: 7) noted that, '[t]he limited evidence that is available suggests that health outcomes are generally worse for Roma than for [the] majority population', citing a presentation entitled, 'Roma Health and Wellbeing in Northern Ireland', which identified healthcare issues for Roma children and adults (Wright, 2011).

In May 2018, the NGO, Friends, Families and Travellers (FFT), was appointed as the Secretariat for the All-Party Parliamentary Group (APPG) for Gypsies, Travellers and Roma (GTR), which replaced the earlier Ministerial Working Group (MWG) for Gypsies and Travellers (United Kingdom Parliament website, as at 6th June 2018). Between 8th March 2018 and 17th July 2018, Baroness Whitaker and Kate Green MP, Co-Chairs of the APPG, asked Parliamentary Questions relating to: Government steps to address health issues in the GTR communities; improvement of life outcomes of GTR people post-Brexit; the development of a comprehensive Roma Integration Strategy; racist hate speech targeted at GTR communities; treatment of Roma with no fixed abode or residents' cards; and monitoring or evidence in relation to suicide rates, and mental health and well-being, of GTR people (Friends, Families and Travellers website, 3rd September 2018).

A submission from the RSG (Shallice and Greason, 2017) to the Women and Equalities Committee inquiry into tackling inequalities faced by Gypsy, Roma and Traveller communities (United Kingdom Parliament website, September 2018) raised the need for monitoring by ethnicity of Roma people on the Census and within the NHS; the absence of culturally competent healthcare for Roma community members; and the distinct lack of research into the health needs of Roma people. The National Roma Network (2017) also responded, raising difficulties resulting from a lack of reliable ethnic monitoring data; the need for recognition of diversity within the Gypsy, Roma and Traveller umbrella term; and mental health issues arising from inequalities experienced by migrant Roma. In terms of the health of Gypsy, Roma and Traveller people, the ensuing report (WEC, 2019) echoed the earlier literature, with its focus on a lack of monitoring and resulting concerns regarding resource allocation. There were no specific comments about the health and well-being of Roma people living in the UK (ibid.).

2.4.3 Lack of research into Roma health and well-being

A frequent comment, seen across the academic and the wider literature, was the lack of research into Roma health in Europe, including the UK (EPHA, 2014; Lane et al., 2014; Ryder and Cemlyn, 2014; TS4SE Co-operative Limited, 2009; Zeman et al., 2003; Hajioff and McKee, 2000). While sections on the health and well-being needs of Roma communities in the UK appeared in a significant number of formal reports, outlining the position of Roma migrants more widely across the EU (Fekete, 2015; European Commission, 2014a, 2014b; Lane et al., 2014; Ryder and Cemlyn, 2014; Willers and Greenhall, 2012), the report authors consistently drew attention to the lack of research in this area. In 2000, Hajioff and McKee stated that:

> The health of the Roma population presents a major challenge to public health professionals, especially in some countries where they are a significant minority and where there may be discrimination, social exclusion and even overt racism. There is a need to explore locally sensitive mechanisms that can begin to understand their health needs and ways of tackling them (Hajioff and McKee, 2000: 868).

Zeman et al. (2003) were interested in broad-based large population studies, which they found to be lacking from the research into the health and well-being status of Roma people. They stated that, 'Roma health issues are under-studied from a comprehensive, epidemiological perspective' and 'Surveillance and population health indices for this international minority population is scarce to lacking in the published literature' (ibid: 223). Of the one hundred and twenty-nine articles they reviewed, '[t]he majority of research (50%) examines the genetic characteristics of this group' (ibid: 223). Zeman et al. suggested that '[b]efore attempting surveillance efforts, qualitative studies should be conducted to understand Roma cultural perceptions of health, illness, health care and healing practices' (ibid: 242).

In 2009, the TS4SE Co-operative Limited quoted the Open Society Institute (OSI) (2009):

> 'Roma health has received little attention in European public health circles. Data about the living conditions and health status of Roma is hard to find.' (TS4SE Co-operative Limited, 2009: 6). A Europe-wide lack of progress is evident through the European Public Health Alliance (EPHA) report (2014), 'EPHA Position on Roma Health in Europe'. This report pointed out that existing data were fragmentary and lacking in good quality information about Roma health, suggesting that systematic research and data collection continued to be needed.

More recently, in relation specifically to Roma communities in the UK, Lane et al. (2014: 4) also stated that, 'Research on the Roma population and their access to health care in the UK is very sparse'. Ryder and Cemlyn (2014: 10), referencing the RSG Mental Health Advocacy Project (2012), noted that, 'There is little research on the health of Roma people within the UK but one study found that the Roma community also had poor physical health, which was worse than amongst other socially disadvantaged and ethnic minority populations in the UK'.

However, during the course of the present research, greater interest was shown in this area and relevant papers were incorporated into the literature review (see 2.1). In addition, a number of initiatives have begun to raise awareness of health and well-being issues impacting on Gypsy, Roma and Traveller communities in the UK (See 2.3.2).

2.5 Social and cultural determinants of Roma health and well-being

Throughout the discussion around the NHS service provision policy response, as well as within the wider literature, numerous references were made to social and cultural factors impacting on Roma health and well-being. In the following sections, these factors are examined, along with the ways in which they are interpreted and acted upon.

2.5.1 Social determinants of Roma health and well-being

The findings of the literature review clearly indicated the impact of structural factors on the health and well-being of Roma people, including the effects of poverty and discrimination in their countries of origin, potentially leading to ongoing difficulties whilst living in the UK. The social determinants of health are well documented, for example, by Marmot and Wilkinson (2006), who consider key socioeconomic factors known to powerfully impact on the health of all populations in modern societies. In relation to Roma communities, the World Health Organisation (2017) states: ‘Roma are disproportionately poor in many countries, and evidence suggests that Roma are concentrated among the most poor. The conditions in which most Roma live have serious consequences for their health’. The uncertain status of Roma individuals living in the UK, generated by the Referendum decision to leave the European Union and mentioned in Chapter one (1.2), suggests further difficulties for this already marginalised collectivity, which may have a detrimental effect on their health and well-being.

Progress in making improvements in this area appears to be slow. In 2003, Zeman et al. noted the relationship between poverty and health status. They stated, ‘Roma peoples are vulnerable or at risk for increased morbidity and mortality because of the factors … which lead to decreased social capital and social status’ (ibid: 241) and they noted that research had linked parental migratory work with poor nutritional status in children (ibid.). They emphasised that, ‘… poverty and near poverty status remains one of the strongest predictors of mental and physical ill-health’ (ibid: 242).

In their discussion of the social determinants of health in relation to Roma people living in segregated communities in Central and Eastern Europe, Parekh and Rose (2011: 140) cited Wilkinson and Marmot (2003), suggesting that:

> It is not simply that more materially disadvantaged people suffer poorer health from experiencing bad living conditions, nutrition and education. In fact, the underlying injustices that result from the social meaning of being poor, unemployed, socially excluded and discriminated against actually brings about a negative impact upon physical health.

The EPHA report (2014: 1) also draws attention to the impact of the social determinants of health on Roma communities across Europe:

> The great majority of the estimated 10 – 12 million Roma population is found at the very bottom of the socio-economic spectrum: they suffer worse health than the other populations in the countries due to their higher exposure to the range of unfavourable factors that influence health. Due to the multiplicity of their discrimination and social

> exclusion, the inequalities faced by the Roma population highlights the cause for combating the social determinants of health across the board.

The EPHA states that data evidence on Roma health inequalities exists '…and shows a public health emergency which requires immediate political actions' (ibid: 1). At the same time, they note that data is limited and lacks good quality information about Roma health. They suggest that systematic research and data collection are needed to provide missing information about the distinctive health needs and patterns of disease among Roma people (ibid.).

In terms of the UK, a significant number of reports refer to the social determinants of health in relation to Roma communities (Newton and Smith, 2017; Warwick-Booth et al., 2017; Smith and Newton, 2016; Willis, 2016; Clark, 2014; McNulty, 2014; FRA, 2012; RSG, 2012; Fremlová and Anstead, 2011; Tobi et al., 2010; Fremlová, 2009; TS4SE Co-operative Limited, 2009). However, the empirical evidence to support, sometimes quite sweeping, statements about the health status of Roma people in the UK is not always clear. Comparisons between the health and well-being of Roma people and that of members of other disadvantaged groups are few. Although the assumption is that the health status of Roma people is worse than that of members of other groups, the absence of monitoring by ethnicity of Roma people in the UK (see 2.3.3), and the resulting lack of data, make empirical comparison almost impossible to achieve.

An interrogation of data obtained from the 2011 Census in England and Wales, looking at variations in health between ethnic groups, clearly shows that '[t]he White Gypsy or Irish Traveller group, identified for the first time in the 2011 Census, has particularly poor health. Both men and women have twice the White British rates of limiting long-term illness, and at each age they are the group most likely to be ill' (Bécares, 2013: 1). No category was included in this census for Roma people, so they are omitted from this interesting analysis. Despite similarities between Romanichal and Kale communities in England and Wales, and Roma groups, it cannot automatically be assumed that Roma people's health status vis-à-vis other minority ethnic groups would be the same as that of those who identified under the 'White Gypsy or Irish Traveller' category. The complex difficulties involved in obtaining empirically accurate data on ethnic inequalities in health are explored in some detail by Nazroo (2003). Nazroo (ibid: 10) concludes that:

> Data often do not contain sufficiently detailed information on the ethnicity of respondents to reflect heterogeneity across ethnic groups and heterogeneity within broadly defined

> ethnic groups. Socioeconomic data are either not collected at all or are collected at very crude levels that are plainly inadequate for drawing comparisons across ethnic groups. Those that are collected invariably reflect current position rather than risks across the life course, and they do not include other dimensions of social inequality, such as experiences of racial harassment and discrimination and geographically based inequalities… Nevertheless, a large body of convincing evidence now supports the possibility that ethnic inequalities in health are largely a consequence of socioeconomic differentials'.

This lack of empirical data was evident within the cross-referencing found in several of the studies examined. The FRA (2012: 30) report states that, '[t]he [Fremlová] 2009 mapping survey found that many Roma, including children and young people, live in poverty, sub-standard accommodation, often shared with other families. Some are destitute. Severe overcrowding often leads to poor health…'. Fremlová (2009), however, notes the difficulty experienced in obtaining accurate data, both about the numbers of Roma individuals living in the geographic areas in which fieldwork was undertaken and, consequently, about all the aspects of life examined in this study. There was a notable discrepancy between the data on Roma provided by local authority respondents and the reality of the Roma participants' experiences, observed through the fieldwork (ibid.).

Similarly, the TS4SE Co-operative Limited (2009: 14) refers to the impact of overcrowding for Roma living in the UK, suggesting that, 'Such overcrowding can have implications for health, with raised incidence of conditions such as respiratory problems, childhood TB, and meningitis'. Again, this resource and information pack cites Fremlová (2009). Sheffield City Council (Performance and Research Team, Sheffield City Council, 2015: 3) also notes that, 'Overcrowding is a major problem, and can affect health...', whilst Migration Yorkshire (2012: 4) state, 'The disparity in health indicators [between the Roma and the rest of the population] reflect poorer living conditions, reduced access to quality healthcare and higher exposure to risks'. In these instances, Sheffield City Council (Performance and Research Team, Sheffield City Council, 2015) cite the Runnymede Bulletin (2011), authored by Fremlová and Anstead. Although this bulletin refers to severe overcrowding leading to poor health, particularly in relation to Romanian Roma, its own source is not given (Fremlová and Anstead, 2011). Migration Yorkshire (2012) cites the European Commission (2011), although the European Commission document addresses the situation of Roma throughout the EU. Migration Yorkshire (ibid: 5) relates the European Commission (2011) observations to the situation of 'Roma communities recently migrated to the Yorkshire and Humber region of the UK'. They note that local research (Rose et al., 2011; Moore, 2010; NHS Sheffield, 2009), as well as anecdotal information from local health practitioners, suggest that factors such as insecure employment, poor working conditions and unhealthy lifestyles contribute to poor health among Roma people living in the UK (Migration Yorkshire, 2012).

In London, Tobi et al. (2010) deemed poor working and living conditions and poor diet to be contributory factors to poor health among their Roma participants, with fieldworkers reported as observing untreated injuries. However, Tobi et al. also found poor housing and living conditions, even in the UK, to be linked to asthma and bronchitis among non-Roma Albanian/Kosovan study participants (ibid.).

2.5.2 Negative impact of prejudice and discrimination on health outcomes, particularly mental health

One of the most notable findings of the literature review was the emphasis of many studies on the impact of racism and discrimination on the mental health of Roma individuals (Smolinska-Poffley and Zawacki, 2017; RSG, 2016, 2015; EPHA, 2014; Lane et al. 2014; Greenfields, 2012; RSG, 2012; Tobi et al., 2010; Zeman et al, 2003). Tobi et al. (2010) noted this strong emphasis on mental health within the health literature on Roma people. This already existing situation is likely to have been exacerbated by the experiences of Roma people throughout Europe during the global health pandemic relating to SARS-CoV-2 (Walker, 2020).

Lane et al. (2014: 42) suggested that some members of the Roma communities may be at risk from mental health problems ‘due to their experiences of persecution, racist attacks, bullying, social exclusion and frequent incidents of rape in their country of origin’. In relation to mental health specifically, Tobi et al. (2010: 15) reported that: ‘a central theme that runs through most health issues related to the Roma is the pervasive impact of experiencing racism and discrimination throughout an entire lifespan and in employment, social and public contexts. The body of evidence highlights high rates of anxiety, depression and at times self-destructive behaviour (for example, suicide and/or substance abuse)’. This study reports that, ‘in their own opinion, the Roma have so many problems that *“every other person is depressed”*’ (ibid: 26, original italics). Among the key recommendations from their Mental Health Advocacy Project, the RSG (2012: 7) suggests: ‘Research to explore the impact of racism and discrimination on the mental health of the Roma’.

Illustrative of the depth of prejudice experienced by Roma families within Europe was the wide reporting in the French press (in early January 2015) of the illegal refusal by the mayor of Champlan, Southwest of Paris, to allow the burial of a Roma baby, who had died from

Sudden Infant Death Syndrome, in the cemetery of the commune in which her parents lived (France 24, 2015; Le Monde, 2015; Le Parisien, 2015; Barbezat, 2015).

2.5.3 Cultural factors impacting on Roma health and well-being

Issues relating to Romani culture nevertheless emerged in a number of reports as having a significant impact on health and well-being outcomes for members of Roma communities (Marsh, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016, 2015; The Social Marketing Gateway, 2013; FRA, 2012; RSG, 2012; Tobi et al., 2010; Poole and Adamson, 2008; Zeman et al., 2003; Hajioff and McKee, 2000). There were strong indications that cultural prohibitions and practices impacting on health and well-being should be understood and accommodated by service providers. These included factors regarding gender, age, mental health and disability. However, assumptions about 'Roma culture' need to be treated with caution.

Aspects of Roma cultural behaviour, particularly cultural taboos, are frequently cited as the causes of barriers to accessing healthcare services for members of these communities, with training and awareness-raising for healthcare professionals being recommended as a way forward (Shallice and Greason, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016). At the same time, it is easy for Roma people to be seen as the cause of their own difficulties by virtue of being 'different' or 'hard to reach', and this notion can be used to legitimise very slow progress in reducing inequalities between Gypsy, Roma and Traveller communities and others (Smith and Newton, 2016: 12). In their research into the social and contextual issues framing the decision-making processes of Gypsy, Roma and Traveller parents, Smith and Newton (ibid.) found little to support the belief that cultural values and practices shaped parental decision making. They suggest, instead, that collective perceptions within Gypsy, Roma and Traveller communities in the UK, in this instance, towards uptake of the measles, mumps and rubella (MMR) immunisation, are adaptive and strategic responses to underlying structural factors, such as poverty, poor living conditions and social and spatial exclusion.

In a study focused largely on English Romanichal Gypsies, Acton et al., (1997), turn the concept of cultural disadvantage on its head, noting that the generalised epistemological assumption that Romani people need to be given knowledge about diseases and symptoms, and a general awareness of health, fails to take account of the basis of Romani concern for health in their ubiquitous practice of a system of washing taboos. They '…suggest that this sense of cleanliness or propriety is the foundation of Gypsy health practices' (ibid: 166). Noting that '[t]he great majority of the literature on various Romani groups makes gender differentiation fundamental to the understanding of Gypsy uncleanliness taboos' (ibid: 167), they point to the traditional summarising of Romani pollution taboos by Gypsylorists as 'the uncleanness of *women*' (original italics) (ibid: 167). As a result, women have been the focus of most public health interventions directed at Gypsies and Travellers in the UK (ibid.). In relation to Romani women, Acton (1998) warns against the danger of linking Romani cultural beliefs about aspects of female physicality as 'unclean' with an idea that Romani women are disempowered by these beliefs. Acton et al. (1997: 176) point out the need for effective health education policy for Romani women and men of all ages and suggest that this requires a move '…from the image of Gypsy women as victims, to the reality of Gypsy women as effective change agents'. A Roma participant in the study by Lane et al. (2014) pointed to disagreement between Roma mothers and health visitors about the way in which Roma children were raised. Health visitors were thought to believe their own methods were better, despite Roma children having been raised in the same way for generations. The participant felt that health visitors should be given a better understanding of Roma culture.

These critiques notwithstanding, cultural taboos did appear to play a part in the reported difficulty for Roma people in accessing health and well-being services. In the study by Tobi et al, (2010), participants stated that many families had children with disabilities, something they found difficult to accept. Disability and mental health were identified as taboo subjects, and community members would try to hide these problems from one another for fear of stigma, which could affect their standing in the community. This resulted in them failing to seek help for these difficulties. A Roma participant in the study by Tobi et al. pointed out the need for education within the community about mental health and disabilities. The report also noted that, amongst Roma communities, attitudes towards homosexuality remain prejudiced, offering little opportunity for issues to be raised by community members (ibid.). A Romanian Roma participant in a focus group organised by the RSG Mental Health Advocacy Project (2012: 60) said, '… Mental health problems must be hidden. There are two major taboos in the Roma culture, sexuality and mental health… Roma usually do not know anything about mental health problems, they fear mental health illnesses…'. The RSG (2016: 1) also notes that, '[a]nything related to female sexual or gynaecological health is considered an unclean object/subject and is to be discussed only amongst females'. They state, as well, that Roma health-related issues should not be discussed in groups where the age gap between individuals exceeds ten years (ibid.). In relation to disability and mental health, it is worth noting that cultural taboos within mainstream CEE communities may also influence Roma taboos regarding these issues. Rasell and Iarskaia-Smirnova (2014) examine the profound complexity of the signification and experience of disability, including mental illness, in post-Soviet countries.

In a study of cross-cultural barriers to the delivery of optimal healthcare for Roma (Gypsy) people in the United States (US), Vivian and Dundes (2004) conclude that an understanding of cultural beliefs and practices is important to the provision of effective service planning and delivery. The authors note that Roma in the US include people from five main Romani subgroups. They suggest that Roma cultural traditions may conflict with the requirements of mainstream healthcare practice, resulting in significant treatment mistakes. Cultural factors identified through this study include 'concepts of pollution, cleanliness, ideal weight, death, and views of medical procedures such as immunizations and surgery' (ibid: 86). Vivian and Dundes also note the need for healthcare providers to understand the importance of family involvement and the hierarchy of age and sex within Roma culture. They recommend education to inform healthcare workers of the most effective ways in which they might work with patients from these groups (ibid.).

Hancock (2002) discusses the healthcare practices of the Vlax Romanies, a grouping to which he himself belongs. He notes the division of diseases into two categories, the first being those seen as natural to the group: '…such things as heart complaints, rashes, vomiting, hiccups, insomnia or irritability…' (ibid: 88). The second category consists of diseases seen as resulting from too much familiarity with the non-Romani world, including all sexually transmitted diseases (ibid.). Diseases seen as natural to Romanies can be treated by a female healer, whilst those linked to the non-Romani world must be treated by a non-Romani physician. In the latter case, the individual may need to be admitted to a hospital, with many relatives and friends visiting the Romani patient. Hancock suggests that, although large numbers of visitors can cause difficulties for hospital staff, this is beginning to be recognised by hospital administrations as cultural behaviour, and to be accommodated (ibid).

Both Hancock (2002) and Acton et al., (1997) refer to the use by Romanies of traditional herbal medicine, with Hancock stating that this knowledge is being lost due to the easy availability of commercial medication. Acton et al. (ibid: 172) suggest that '[m]aybe neglected folk herbal remedies should be examined to see if they should be added to the battery of therapeutic tools. Sutherland's (1992) examination of the *materia medica* of Vlach Rom in California suggests this is worthwhile'.

Within a somewhat broader context, Brian Alleyne (2002: 607) cautions against, '… an unreflexive use of the concept of community as the privileged container of cultural difference'. Alleyne critiques the concept of the 'ethnic community' (ibid: 608), which he suggests is frequently used in sociology without examination either of its construction within post-colonialist conceptions of 'the West' and 'the Rest', or of the position of sociology and sociologists within, and contributing to, this construction (ibid: 611). Alleyne advocates a 'more reflexive sociology of community' (ibid: 615), in which 'culture' is seen as being both made by people and making people (ibid.). He states:

> Culture, however conceived, is always implicated with power, and by implication so too is the community which is constituted by and in turn constitutes culture. It is often in the interests of the powerful to believe that culture is somehow natural, given. It is often a source of comfort to the dominated to share this belief. Unreflexive notions of community often serve to hide the constructedness of culture, and the culture of community construction (ibid: 615).

2.5.4 Trafficking and exploitation of children

A scenario in which cultural and structural factors are often conflated in relation to Roma communities is that of trafficking and exploitation of children. A presentation made at a meeting of the National Roma Network (NRN) in April 2016, as part of an item looking at the safeguarding needs of Roma children in UK schools, noted that European studies report the vulnerability of young Roma children to sexual exploitation and abuse across Europe (Allen, 2016). Allen stated that the extent and nature of child sexual exploitation in the UK, including experiences of Roma people, has not been studied in the same depth as it has in other parts of Europe (ibid.). Allen's research, '[p]rovides proof of principle, though not of fact, that young Roma people are at significant risk of [child sexual abuse] in the North of England' (ibid: 2), although this is certainly not a Roma-specific problem (Barnardo's, 2012). Allen noted that his research (2016) focused on child sexual abuse and not on betrothal, or arranged or forced marriage.

Anecdotal evidence from Allen's research suggested some Roma families living in fear of criminal gangs and lacking the English language skills needed to be able to defend themselves through the criminal justice system (ibid.). The research noted the need for young Roma people to feel socially included, and to be given a voice, in order to avoid vulnerability through marginalisation, and recommended teaching them about the risks and threats of child sexual abuse. The issue of community-based shame and denial also needed to be openly discussed, to avoid young people's continuing vulnerability through a sense of guilt (ibid.).

Within its list of priorities for non-discrimination and citizenship, 'The Strasbourg Declaration on Roma' states, 'Combat trafficking (29) Bearing in mind that Roma children and women are often victims of trafficking and exploitation, devote adequate attention and resources to combat these phenomena, within the general efforts aimed at curbing trafficking of human beings and organised crime, and, in appropriate cases, issue victims with residence permits' (Council of Europe, 2010: 3). The European Roma Rights Centre (ERRC) and People in Need (2011: 51) report on trafficking of Roma people notes that:

For example, in Bulgaria, respondents to this study highlighted the vulnerability of Romani children from poor families to trafficking. Children aged six to fifteen from the Romani minority and orphans are reported to be at the greatest risk of trafficking for sexual exploitation. In Romania, the high vulnerability of Romani street children to trafficking was highlighted. In Slovakia, respondents perceived the exploitation and trafficking of Romani children to be growing. Several of the most important factors that increase the vulnerability of children to trafficking include being subjected to domestic violence, placement into state care or dropping out of school.

Although the ERRC and People in Need study was undertaken in Central European countries, the report contains a number of references to instances of trafficking of Romani individuals, including children, to the UK. The same report also notes the negative impact on health and well-being, of 'child marriage, as a subset of forced marriage, [which] continues to be practiced in certain Romani communities' (ibid: 71). One of the central issues raised by the ERRC and People in Need study is the need to avoid racial stereotyping of Roma, whilst ensuring, at the same time, the same protection for members of Romani communities as others receive (ibid.).

In addition to literature obtained from academic journal articles, policy documents, books and media articles, relevant information can also be found through television and film. A 'BBC Scotland Investigates' television documentary, broadcast in May 2017, examining the world of human trafficking, shone a shocking light on the alleged plight of Roma community members in Central and Eastern Europe (BBC Scotland Investigates, 2017). Although it is wise to be cautious with regard to television journalism (Fremlová, 2009), which often portrays Gypsies, Roma and Travellers in a negative or sensationalised light, this particular programme did seem to contain some content worth noting in relation to this study. The scenario described in this documentary suggests potential risks to the well-being of some Roma women, men and children.

People trafficking is now the second most lucrative form of criminal activity, worldwide, beaten only by drug dealing in its potential financial profit for the traffickers. This documentary investigated the alleged sale of young Roma women into prostitution and domestic slavery, and of Roma men into deeply exploitative underground labour markets. It was suggested that older Roma women, also, are being sold into the begging trade. The programme focused on communities in Slovakia and in Romania and claimed that the main destination for those being trafficked was the UK, with Glasgow as a significant hub for these activities (ibid.).

Underpinning this situation is clearly the abject poverty in which huge numbers of members of Roma communities live, in segregated areas, in CEE countries. This has continued, despite the requirements of the EU for improvements in the living conditions and state provision for Roma communities in Romania and Bulgaria, as a condition of EU membership (RSG, 2012). These requirements have not been met, and the age-old attitudes of disaffection and prejudice towards the Roma have worsened in many respects since the collapse of the Soviet Union in 1991.

The documentary proposed that traffickers came from both the mainstream communities of the countries concerned and, also, from within some Roma communities themselves, where poverty has given rise to organised criminal networks. In an ironic twist, the EU Freedom of Movement Directive has led to one particular aspect of trafficking of young Roma women, whereby they are traded as ‘brides’ for men from Asian communities, living in the UK, who seek to obtain UK residency through marriage to EU citizens. A right that should offer the freedom to travel within the EU, to seek better circumstances, has become for some the key to their imprisonment. Lured by the promise of a better life, or sometimes sold by their own families, significant numbers of young Roma women are, allegedly, being systematically abused with little hope of rescue (BBC Scotland Investigates, 2017). Many of these women, having been traded into a fake marriage, give birth to children who become pawns in the criminal game. If the name of the father is not recorded on the child’s birth certificate, both mother and child can subsequently be re-sold to another Asian man, who can claim to be the child’s father, thus seeking to remain in the UK through the right to a family life (ibid.).

A similar story was reported in 2015, when members of a Slovak Roma gang based in Kent were jailed for trafficking women into the UK, allegedly selling them as wives, mostly to Indian and Pakistani men seeking to obtain EU citizenship in order to remain in the UK. The prosecuting lawyer stated that, if the women were not deemed suitable as brides for the purchasers, they would be offered to other men, or forced into prostitution (Boyle, 2015). One of the women victims of this group was noted to have had mental health difficulties prior to the experience of being trafficked (ibid.). However, there is a path to be walked between the outcomes of discrimination and discrimination itself. In 2008, raids carried out by the Metropolitan Police in Slough, to ‘rescue’ Romanian Roma children alleged to have been trafficked into the UK to work as pickpockets, led to all but one of the ten children taken from their families by the police being returned the following day. No evidence was found to show that the adult suspects had been involved in any criminality involving their children (O’Neill, 2008). O’Neill makes the point that the negative publicity that surrounded this episode simply served to reinforce public prejudice against migrant Roma families and towards immigration in general (ibid.).

The implications for the mental health of those women who have been trafficked, and of their children, now and in the longer term, are horrifying to contemplate. The experience of abuse at the hands of strangers and, sometimes, in a sense, by their own families, adds a qualitatively different layer to the historic endemic prejudice towards the Roma communities, the cultural prohibitions, and the structural barriers to accessing healthcare services experienced by Roma people in the UK in general. To be imprisoned and abused is not only damaging at the most fundamental psychological level but is also likely to prevent physical access to many services. Where trafficked Roma women do encounter healthcare professionals, fear of the consequences will inevitably prevent any action which might enable access to mental health care. For the children of these relationships, growing up in fractured families, with damaged mothers and complex questions of identity, the long-term future looks bleak, and there may well be a generation in which some psychologically damaged Roma children need, but do not receive, mental health care.

2.6 Discussion of main literature review

The literature review revealed a wide range of items of various types including, but by no means limited to, academic research. The literature examined is testament to the scope and complexity of the field of the present study. This complexity includes at least five major aspects: the size of the Romani collectivity worldwide and its diversity; the scale of EU governance and the place of healthcare within its broad approach; a system of devolved healthcare in each of the four nations of the UK; the vast range and complexity of health and well-being themselves; and the difficulties, for Roma people themselves and for everyone else, in disentangling the realities of their lives from the mythology arising from centuries of ongoing prejudice and discrimination.

The present study is set within the context of ongoing funding cuts in the UK and the resultant pressure on NHS services and, initially, was set within a wider framework of European regulations and requirements. The interaction between these European and national contexts has resulted in complex questions about the responsibility for the health and well-being of Roma people, and a situation in which progress in making improvements appears to be slow. The passing of responsibility for the inclusion and general well-being of Roma people between the EU and Member States has led to them being caught in a place where political bodies at all levels wish to be seen to be taking the issue of Roma inclusion seriously but, in fact, do very little to make concrete changes for the better. With the exit of the UK from the EU, it is quite possible that the requirement for Roma inclusion might be viewed as a problem that will go away, although many Roma people will remain in the UK. The recognition of the need to include members of marginalised groups in the process of setting goals for programmes designed to benefit their communities was echoed by studies looking at Roma health and well-being (Willis, 2016; The Social Marketing Gateway, 2013; Migration Yorkshire, 2012) but, with no structured programme in place in the UK to address their needs, this is unlikely to happen.

Wide-ranging health and well-being needs of Roma people were described throughout the literature, with an early focus on communicable disease and its threat to majority populations. The literature also reported many other health and well-being issues amongst members of Roma communities in the UK, although the evidence base for these claims was very variable. Despite these apparent health needs, many barriers to accessing services were identified. There was, however, a strong localised response from NGOs in areas where there are large Roma populations, which identified and initiated positive strategies for promoting successful access to healthcare services for Roma people.

Twenty-seven items were initially identified that included a focus on the health and well-being of Roma people in the UK. Thirteen were written by NGOs, five of which were produced by one organisation, with others having overlap among their authors. There was also some academic interest, with eight studies looking at Roma health and well-being in the UK. Five items were produced by national or local authorities, and one study was of uncertain origin. The location of these studies and reports showed ten being based on research in three areas with high Roma populations: Yorkshire and Humber, Northeast London, and Govanhill in Glasgow, Scotland. Whilst it is understandable that research is undertaken in geographical areas of the highest need, this does not necessarily communicate a picture of the health and well-being needs of Roma people across the UK, or across the whole of London. It is also possible that organisations that are very proactive in this field may tend to use the same groups of Roma participants in their different studies. Issues regarding recruiting representative participant cohorts are discussed in Chapter four. A further two items were later identified, one of which was a national report, written by a government organisation (WEC, 2019), with the other being academic and focused also on the Yorkshire and Humber area (Swanwick et al., 2018).

There was some attempt by NGOs to empower NHS staff regarding the health and well-being needs of Roma people, but there was no evidence of responsive structural change within the NHS. In some cases, guidelines for healthcare staff working with Roma patients have been produced (RSG, 2016; Migration Yorkshire, 2012; TS4SE Co-operative Limited, 2009). Where guidelines or training have been offered, healthcare professionals have been interested in learning about Roma culture and how they can improve their services for Roma people (Smolinska-Poffley and Zawacki, 2017). However, their capacity to alter their practice accordingly is limited by the current resource pressures on the NHS. From this, it might be inferred that there is a wish to change, but that this is being prevented by the structures of the NHS. Because there is no national NHS strategy regarding Roma health and well-being, it is unclear whether the input of NGOs has had a significant impact on local NHS services - this is likely to be patchy and piecemeal. Certainly, there is little evidence to indicate whether NHS services are responsive to advice from the voluntary sector.

The lack of specific NHS guidance regarding the health and well-being of Roma people suggests that the absence of NHS monitoring by ethnicity of Gypsy, Roma and Traveller groups renders them almost invisible in UK healthcare policy and planning. Although monitoring by ethnicity has been critiqued, in terms of both its accuracy and the potential dangers of its racialising nature, such monitoring could help to provide the information necessary for positive change to take place within the NHS. Although monitoring by ethnicity fails to capture diversity of experience or of need within its broad categories, it could be seen as an opportunity to utilise strategic essentialism (Landry and MacLean, Eds., 1996) in the process of gaining recognition and improved services for members of Roma communities. The poor response by the UK government to the EU requirement for an NRIS, and the absence of a strategic approach to research in this area, have reinforced inconsistency across the UK.

A significant number of studies identified cultural factors affecting Roma health and well-being. However, the impact of structural factors clearly played a significant part in determining health and well-being outcomes for Roma people living in the UK. The strong focus within the literature on the negative impact of discrimination, poverty, poor accommodation and insecure employment on Roma health and well-being appears to support Nazroo's (2003) assertion that, despite the inadequacies of data collection on ethnicity, existing evidence suggests that ethnic inequalities in health generally appear to arise largely because of socioeconomic differentials.

In the case of Roma people, the negative impact of prejudice and discrimination on mental health was one of the most marked features of the literature examined, although only one study looked specifically at Roma mental health (RSG, 2012). The stress within the literature on this aspect of Roma health and well-being strongly endorses the prioritising by the European Commission (2017) of measures to challenge discrimination and anti-Gypsyism alongside the four key policy areas of the EU Framework and the NRIS, if Roma inclusion interventions are to be successful. At present, discrimination and socioeconomic inequalities appear to be key factors underlying significant mental health issues amongst Roma people, but these are understood within Roma communities as being genetically, rather than environmentally, caused, leading to a failure to seek help for these difficulties (RSG, 2016). The RSG (2012) notes that '[m]any Roma community members have a strong belief in the genetic transmission of mental health issues, which can lead to diminished marriage prospects both for people suffering from mental health problems and their family members'.

Throughout the literature, Roma people in Europe are overwhelmingly described in ways that homogenise their differences and separate their experiences from those of other minority communities. However, the influence of the cultures of host countries, intermarriage, proximity to other cultural groups, and the agency of Roma people themselves, warn of the dangers of an unreflexive use of notions of ‘Romani or Roma culture’. The uncertainty as to whether they should, or should not, be viewed through the lens of ethnicity has led to their separation from other migrant groups, who are constructed as minority ethnic communities. In addition, Roma people in Europe appear to sit at a level below that of other citizens of all other European countries, notwithstanding the differing relationships existing between these countries themselves.

However, within the literature there was some recognition of the diversity amongst Roma communities (National Roma Network, 2017; Brown et al., 2016; McNulty, 2014; RSG, 2012, 2010), and the distinction between Roma people and Gypsies and Travellers (Shallice and Greason, 2017). There was also acknowledgement that Roma people share experiences with other migrant groups (Clark, 2014; Equality Commission for Northern Ireland, 2014; McNulty, 2014; Tobi et al., 2010), and that not all identified health and well-being issues are Roma-specific (Tobi et al., 2010). Clark (2014) also noted the way in which intercultural exchanges counter stigmatising narratives about Roma people. Nevertheless, the representation of Roma people as homogenous and different from other migrant citizens of EU member states remains a strong critique of much of the literature examined and contributes to maintaining the exclusion of members of Roma communities.

Looking at the existing literature, there are further limitations to the studies that have been conducted around Roma health and well-being in the UK. Firstly, the quality and the methodology behind the studies is very variable. Where NGOs undertake several research studies, the sampling is potentially taken from the same populations, raising questions as to how representative these cohorts are, given the localised nature of the research and the fact that people who participate are often the least disadvantaged.

For most of the studies examined, the epistemological position is either not stated or may be assumed to be embedded within the research method chosen, for example, participatory action research (Marsh, 2017), but the epistemological implications are not reflected upon. This makes it difficult to have a clear sense of how the findings may be intended to be used. Most studies, including reports drawn from other literature, do not clarify whether the findings are knowledge that accurately reflects Roma health and well-being experiences and needs, as opposed to, for example, one particular interpretation.

The exceptions are Smith and Newton (2016) who use a critical realist framework, and Clark (2014), who gives more consideration to epistemology, noting that most studies looking at the situation of Roma across Europe approach it through the lens of ethnicity. Clark suggests that this does not take account of other categories of identity such as gender and class. Clark uses an intersectional approach, with reference to feminist theory, and a micro sociological and ethnographic approach within a wider European and UK political and policy context. He notes the limitations of research with Gypsy, Roma and Traveller communities tending to be seen through '…a highly racialised and/or ethnicised lens…' (ibid: 3). The assumption would be that differences found are due to ethnicity exclusively, with ethnicity as the key to why the Roma are singled out as different, this being the role of the category of ethnicity. Clark draws attention to the dangers of this view, which he sees as reductionist and lacking critical thinking, and which fails to take account of issues such as gender and class, and how these connect to notions of 'race' (ibid: 4), which are, themselves, social constructs (Kohn, 1996).

For most of the studies, the findings were not checked back with the Roma participants to establish their views about how accurately they reflected their experiences. Focus groups were often used which offered opportunity for conversation, but which could be inhibiting for some participants and the outcome is a consensus view, which might conceal individual experiences. There are also certain culturally taboo subjects which might not be discussed in a group. There was a strong sense within the literature of the Roma as lacking in agency in relation to their health, and as being constructed as victims of the lack of government response, and there was a lack of discussion about the way in which Roma people are positioned in relation to their health and well-being. This notable absence of critical thinking about the role of the Roma in relation to their own health and well-being sees them largely constructed as passive victims of centuries of discrimination. There is a danger of this construction underpinning studies conducted by voluntary sector organisations, which may reflect the aims of such organisations as providing help to a group perceived to be innocent, deprived and unable to help themselves. There are some exceptions whereby the Roma are given the opportunity to participate in improving health service provision (Marsh, 2017; Brown et al., 2016; Willis, 2016; RSG, 2012). Where the opportunity is given, it is clear that Roma people do wish to engage with this. These studies look at the importance of empowerment of the Roma in relation to their health and well-being; however, the assumption is that they need to be empowered rather than questioning whether they feel they need or want this.

Only three studies individually interviewed Roma people, sometimes as part of a mixed methods design (RSG, 2012). Marsh (2017) is an example of a study which used interviewers from the local Welsh communities who had been trained to carry out this task. However, this could bias the study as, in this situation, the participants may not feel totally free to express their views. It is also impossible to establish how many Roma were interviewed in this study, as this was a mixed sample with other Gypsies and Travellers and the numbers from each group were not stated. The study also has only one participant quote, with no indication given of which group this individual was from. Furthermore, the views of professionals are also included; however, the findings are presented without differentiating what was said by whom.

Willis (2016) worked in Sheffield, using '…a social view of the determinants of health inequalities' (ibid: 56), which is Marxist in its approach and is based on an assumption regarding the causes of inequalities in health, although it is helpful that this is stated. Within this study, significant efforts were made to use an interviewing strategy which would enable participants to communicate in the Romani language. However, in the process of preparation for fieldwork for the present study, this researcher found that Roma individuals indicated that they did not wish to be interviewed in the Romani language, as they would not feel comfortable speaking about their health needs with another Roma person. There is also the question of whether Roma interviewers would be motivated in this position towards eliciting particular views or presenting a particular picture. The study by Willis (ibid.) was also very specific, as it focused only on Slovak Roma in Sheffield.

The RSG (2012) study looked at the outcomes of their Roma mental health project, a very specific area of health and well-being, and was evaluated by the staff who ran the project, working with an external evaluation consultant, as a 'critical friend' (ibid: 36), which may have compromised its objectivity. The RSG generally interviews users of its own services, which could bias the outcomes, as could the potential impact of project funders on the impartiality of research.

The studies which look at Roma health and well-being in the UK gave limited recognition of the context of the European requirements for a strategic approach at a national governmental level. Fremlová (2009) situates her study in the context of EU free movement, while Poole and Adamson (2008) refer to the Decade of Roma Inclusion, although both studies predate the Framework for NRIS. Brown et al. (2016), Willis (2016), McNulty (2014), The Social Marketing Gateway (2013) and the FRA (2012) did refer to the European context, with The Social Marketing Gateway (2013) placing the situation of the Roma in Scotland firmly within the context of EU requirements for member states to promote the social inclusion of Roma populations. The remaining items identified, however, did not refer to the European requirements. The Equality Commission for Northern Ireland (2014) did not refer to the Decade of Roma Inclusion, or to the Framework for NRIS, but did include Roma in their generic racial equality policy.

In reviewing the literature overall, there appeared to be a number of methodological factors which led to potential biases in the interpretation of the findings. The present researcher was struck by the absence of a study which focused on the health needs of Roma people whilst, firstly, taking steps to recognise and limit, as far as is possible, those biases and, secondly, to critique the position of Roma people in relation to their health and well-being. The present study was initially located within the context of the European guidance, looking at Roma health and well-being experiences in London, with a focus on the ways in which Roma health and well-being is constructed, and on Roma agency, Roma self-representation, and the ambiguous positioning of Roma people in terms of ethnicity. The researcher was interested in how the opportunity for Roma agency is created or inhibited at different levels – the EU, national governmental, the NHS, the voluntary sector, within Roma groups and by Roma people at the individual level. This analysis of the literature about Roma health and well-being in the UK, together with the literature discussed in Chapter one, led to an interest in the use of a post-structuralist problematising of the concepts that form the theoretical framework of the present study.

2.7 More recent literature

A further review of recent literature regarding the health and well-being of Roma people, in London and across the UK, was undertaken as the present study proceeded. The studies examined showed the continuation of many of the issues described in the main literature review but with both major, and more subtle, developments. The decision by the UK to leave the EU (Brexit) removed the UK from the earlier, broader European context and, as a result, from European-wide policy and strategy regarding Roma health and well-being, but with no clear UK policy to replace these. Roma migrants in London and throughout the UK, whilst dealing with the impact of the Brexit vote, and the major threat this posed to their citizenship status, were subject at the same time to the global Covid-19 pandemic, with its serious implications for their health and well-being.

Issues regarding the governance of work and in-work welfare benefits for migrant Roma also suggested a negative impact on their health and well-being. Alongside this somewhat bleak picture, however, there was an increasing emphasis on Roma resilience and agency, and the voices of Roma people themselves, along with some degree of challenge to more traditional methods of research into the experiences of Roma migrants and their health and well-being. The earlier, extremely limited, statement of theoretical position discussed in relation to studies in the main literature review was found to have been replaced by a broad leaning towards intersectional theory (Crenshaw, 1991, 1989), as appropriate for research into the health and well-being of Roma people.

2.7.1 The European and UK policy context and current concerns

EU directives and strategy

Within the overall European context, the most significant recently-published document is the EU Roma strategic framework for equality, inclusion and participation for 2020 – 2030 (European Commission, 2020). This framework updates and replaces the earlier EU framework for national Roma integration strategies up to 2020 (European Commission, 2011). The renewed EU framework (European Commission, 2020) once again calls on Member States to devise a national Roma strategic framework to meet its requirements, including both generic and country-specific objectives. The new document notes that '…overall **progress in Roma integration has been limited** over the past 10 years, even if there are significant differences across policy areas and countries' (original emphasis). The greatest progress is noted in the area of education. In relation to health, the framework states: 'Poverty risk and self-perceived health status of Roma improved but medical coverage continues to be limited' (ibid: 2).

The renewed framework (ibid.) notes the damaging impact of the Covid-19 pandemic on the health and socioeconomic circumstances of already excluded and marginalised Roma communities. Antigypsyism, hate crime and trafficking in Roma, in particular women and children, are stated as being continuing matters of high concern (ibid.). Taking an intersectional approach, the framework contains both cross-cutting and sectoral objectives and places the fight against antigypsyism and discrimination centrally, along with promoting meaningful Roma participation, and recognising diversity amongst Roma people. Under the generic aspect of improving Roma health and increasing effective equal access to quality healthcare and social services, the key objective relates to cutting the life expectancy gap between Roma people and the general population by at least half, thereby ensuring '…that by 2030 Roma women and men live five years longer' (ibid: 5).

The new framework (ibid.) sits within the context of existing EU legislation, regarding non-discrimination and equality, including racial equality. The ability to measure progress as essential is stressed, and EU support includes the use of a portfolio of indicators for monitoring the progress of targets set within individual Roma strategies in the Member States (FRA, 2020). Nevertheless, Zaharieva (2020), writing for the EPHA, critiques the renewed framework. Zaharieva (ibid.) notes the lack of progress made in reducing the gap between Roma and non-Roma people, in relation to health, despite the previous EU Framework (European Commission, 2011). Reasons for this include the lack of legally binding mechanisms in this context. Zaharieva suggests that achieving the new life expectancy target requires identified measures to address the social determinants impacting negatively on Roma health (Zaharieva, 2020). Direct measures to tackle inequalities in health outcomes should address unequal access to health coverage, prevention of chronic and non-communicable disease, poor nutrition and prevention of obesity among children (ibid.).

In addition, Zaharieva suggests that an opportunity has been missed to create measurable targets in mental health prevention and protection, as well as unmet needs and ethnic segregation in hospitals, clinics and maternity wards. Zaharieva (ibid.) praises the integration of antigypsyism into the new EU framework but, noting that responsibility for improvements in health equity rests largely with the individual national governments, suggests a need for reviewing the role of the EU itself, to tackle wider challenges.

Throughout the renewed EU framework (European Commission, 2020), the need for an intersectional approach is stressed, to provide for the diversity and needs of specific groups within the Roma population. Noting '…how different aspects of identity can combine to exacerbate discrimination' (ibid: 7), the framework requires national measures addressing the needs of groups including '…Roma children, women, young people, older Roma or those with disabilities, EU mobile citizens, non-EU nationals, and stateless Roma' (ibid: 8). This approach, particularly in relation to multiple discrimination against Roma women, aligns with the European Commission campaign on combating gender stereotypes (ibid.). Zaharieva (2020: 3) states that '…EU Member States must adopt now integrated and holistic Roma Equality, Inclusion and Participation Strategies… for ensuring the health protection of vulnerable Roma groups, such as elderly, people with disabilities, women, LGBTQI+ persons'.

This focus on the health and well-being needs of Roma women appeared in several other studies within the more recent literature (Hughson, 2021; European Economic and Social Committee (EESC), 2020; FRA, 2019; United Nations Population Fund (UNFPA), 2019). Again, taking an intersectional approach, Roma women can be seen to face institutional racism, classism and sexism, both within and outside Roma communities (Hughson, 2021). Writing about Roma women in Romania, Hughson (ibid.) refers back to the historical forced sterilisation of Roma women in southeastern Europe. This experience is also described by Fraser (1995), who discusses coercive sterilisation of Romani women in the post-war Czech and Slovak lands, as well as the forced sterilisation of Romani women that took place in Nazi-occupied Europe during the Second World War.

Hughson (2021) relates this historical experience to current political discourse regarding fertility and the control of women's bodies, with Roma women being viewed as too fertile and as having too many babies. However, many Roma women today lack access to sexual and reproductive health services (ibid.). The EESC (2020) and the UNFPA (2019) note the needs of young Roma mothers, in relation to the care of their own health, along with that of their babies, as well as their need for educational and employment opportunities. Hughson's article (2021) notes the negative impact on women's well-being of wider issues, such as poor-quality housing and, echoing Acton et al. (1997), points to the power and ability of all women, including Romani women, in managing households, caring for the elderly and working within communities. The FRA (2019) calls for gender-sensitive inclusion measures, designed and implemented together with Roma women, and for a strong and prominent voice to be given to Roma women in public and community settings. Closely linked to the health and well-being of Roma women are the health and well-being of their children. The EPHA (2020: 1) states: 'Child poverty and exclusion have devastating consequences for child physical and psychological development, especially in the first 1000 days of life when growth is particularly intensive'.

Roma health mediator programmes have been seen as positive strategies for ensuring equal access of all Roma people to the healthcare system, in Europe and in the UK (EPHA, 2014; European Commission, 2014a; Council of Europe, 2010). In CEE countries with large Roma populations, Roma mediators have become a common aspect of attempts to improve Roma inclusion and outcomes, particularly in the fields of health and education (United Nations Children's Fund (UNICEF) (2017). UNICEF (ibid.) reports that Roma health mediators have been instrumental in improving the quality of life for Roma families, with greater access to healthcare for Roma families and children, and a significant reduction in the mortality rate among Roma children living in Roma settlements. Access to education and social welfare systems has also been improved through the work of Roma health mediators (ibid,). Zawacki and Ferranti (2021), citing the European Commission (2014 [b]), Roman et al. (2013) and the FRA (2018), note that Roma health mediator initiatives in Romania, Bulgaria and Slovakia have produced positive outcomes in relation to increased use of health services, vaccination uptake and patient satisfaction.

Nevertheless, UNICEF (ibid.) notes that child mortality and poor developmental outcomes remain dramatically worse among Roma children than children within the general population. As a result, UNICEF (ibid: 3) promotes the institutionalisation of Roma health mediators as a 'unique' and proven way to overcome these identified problems.

However, the very idea that mediation is necessary, in order to bridge a perceived distance between Roma people and everyone else, implies and reinforces a concept of significant difference. Citing Kóczé (2019), Petraki (2020: 78) posits that the institutionalisation of Roma bridging mediators reflects '…prevalent discourses about Roma as "underdeveloped" and culturally "Other"'. Kühlbrandt (2019), writing about Roma women's access to family planning in Romania, suggests that, whilst social determinants, including financial barriers, shape access to services, issues relating to health and accessing health services among Roma community members are often believed to be connected to Romani culture. Kühlbrandt (ibid.) notes, though, a lack of relevant, good quality critical research and a failure to ask Roma people to identify their own health concerns.

In this context, Roma health mediation can be seen as a cultural intervention, whereby it is assumed that Romani people are best placed to communicate with other Roma (ibid.). Kühlbrandt (ibid: 86) recounts the opinion expressed by a medical practitioner, who saw '…the Roma population as a problem for Romanian society; undesirably deviant and Other'.

This view of Roma people as ‘Other’ is sharply challenged by Petraki (2020: 73), who sees a ‘…problematic consensus narrative that is reinforced through its formulaic repetition’.

Petraki (ibid: 77) cites Kühlbrandt (2017), who developed the term ‘consensus narrative’, particularly regarding the prevailing narrative about Roma people’s relation to the health sector. Petraki (ibid: 77) notes also the development in 1988 by Spivak of the term ‘epistemic violence’, to speak of colonial discourses of knowledge produced in relation to the constitution of colonial subjects as ‘Other’. She notes the central role of the health sector as a governmentality field perpetuating ‘epistemic violence’ towards Roma people and refers to Foucault’s (2008) concept of biopolitics.

Petraki (ibid.) discusses Kühlbrandt’s (2017) work, looking at the narrative reproduction in academic and policy literature, where continuous cross-referencing sustains a consensus narrative in relation to Roma health. She cites Clark (2018), who sees Roma mediation programmes in health and education as conforming to a ‘social inclusion’ model, which denies Roma people independence, agency and the ability to articulate their own need (ibid: 78). This process of knowledge production within the empirical social sciences leads to ‘epistemological violence’ against the Roma (ibid: 78). Teo’s concept of ‘epistemological violence’, cited by Petraki (ibid: 78), sees the researcher as subject and the ‘Other’ as object, leading to the production of an interpretation of data, presented as knowledge. This interpretation then leads to an action, such as the perpetuation of Roma health mediator programmes.

The Roma health mediators in Petraki’s research (ibid.) largely positioned themselves as apart from, or superior to, the Roma communities they were to work with. However, Kühlbrandt’s Roma mediators described the experience of their work as insecure and potentially culturally damaging to themselves (Kühlbrandt, 2019). Kühlbrandt (ibid: 100) offers, as an alternative model: ‘A more dialogical form of mediation, based on conversation and engagement rather than encouragement and enforcement…’. Similarly, Petraki (2020: 73) suggests ‘…cross-disciplinary collaboration, participatory action research (PAR), (self-)reflection, critical theory, and the dialogic creation of scientific knowledge’.

UK policy and strategy

The poor response by the UK to the requirement for a national Roma integration strategy (NRIS) between 2011 and 2020 was discussed in section 2.4.1 (Fekete, 2015; European Commission, 2014a; European Commission, 2014b; Lane et al., 2014; Ryder and Cemlyn, 2014; Willers and Greenhall, 2012). However, since January 2021, when new regulations came into force, following the UK's exit from the EU, Roma people living in the UK no longer have even this very limited protection. A new UK Gypsy, Roma and Traveller National Strategy was due to commence in the spring of 2020 (Ministry of Housing, Communities and Local Government and Lord Bourne, 2019). Subsequently, though, with the interruption of the Covid-19 pandemic, very little has emerged from this strategy, other than some support for Gypsy, Roma and Traveller children's online education during the lock-down period (Ministry of Housing, Communities and Local Government and Lord Greenhalgh, 2020).

More recently, however, The Public Services Committee has written to the Chief Medical Officer and to the Secretary of State for the Department for Levelling Up, Housing and Communities, outlining the difficulties faced by members of Gypsy, Roma and Traveller communities, particularly regarding healthcare. The RSG (2022) states that the Government was asked questions relating to Gypsy, Roma and Traveller health inequalities, lack of health data around Gypsy, Roma and Traveller health outcomes, poor delivery of public services to Gypsy, Roma and Traveller communities, educational barriers, involvement of Gypsy, Roma Traveller communities in co-designing public services, and designing preventative services to improve health outcomes for Gypsy, Roma and Traveller people. Response to this letter has acknowledged a significant issue needing to be addressed, with the ONS actively working to improve Gypsy, Roma and Traveller health data (ibid.).

In a study of the experiences of CEE Roma in accessing UK health and public services, Zawacki (2019) found that barriers to health services reflected unconscious bias towards patients from migrant and deprived backgrounds, rather than direct discrimination. Zawacki (ibid: 250) locates this health service experience within the wider picture of public service provision in the UK, and notes '…the ways in which intersecting influences of discrimination, material deprivation and migration experiences can make [Roma people] invisible within public service institutions'. Zawacki found that, often, it was the most vulnerable, with the most complex needs, who encountered the greatest barriers to adequate healthcare.

Zawacki (ibid.) suggests that instability arising from immigration experiences damages Roma people's belief that they have equality with others, in relation to their life chances in the UK, and highlights the inextricable link between immigration experiences and well-being, following the Brexit referendum. She recommends the adoption of greater sensitivity to experiences of discrimination and unconscious bias against Roma people within the practice of healthcare professionals, public service providers and policy makers, along with a more holistic model of service delivery.

Despite this enduring landscape of discrimination and negative bias towards Roma people, reported within both the main and the more recent literature, and the recognition of the impact of this on the mental health of Roma people, Roma mental health remains an under-researched area (ibid.). In a second self-evaluation report of the RSG Mental Health Advocacy Project, Zawacki and Ferranti (2021) describe the success of the project in achieving its goals. These related to identifying barriers encountered in accessing mental health services and ways in which project beneficiaries managed these, as well as assessing the effectiveness of the project's peer support model, and the response of mental health professionals to the project's Roma cultural awareness training.

Project beneficiaries were supported in overcoming barriers relating to digital exclusion during the pandemic, language support and sustained continuity of access to services, as well as cultural issues inhibiting talking about mental health problems. Training provided for healthcare professionals resulted in a reported increase in awareness of Roma culture, discrimination against the Roma and the circumstances of disadvantage in which many Roma people live. Peer support group meetings appeared to be particularly helpful for project beneficiaries, as these facilitated discussion and provided information and initial contact with mental health professionals, thereby beginning to address Roma cultural stigmatisation of mental health conditions and the lack of words within the Romani language for mental health experiences. However, despite the knowledge gained through the running of this NGO project over many years, it remains locally focused, and its understandings have yet to be adopted more widely across the UK. Zawacki and Ferranti (ibid: 8) note that, even among London boroughs with significant Roma populations: 'Only two of these local authorities (Haringey and Ealing) specifically include CEE Roma in their health needs assessments (as of summer 2018)'.

Kapadia et al. (2022) carried out a rapid evidence review of ethnic inequalities in healthcare across the UK. The focus of this review is on tackling health inequity in relation to ethnicity in the NHS, and on the impact of experiences of structural, institutional, and interpersonal racism on healthcare. Roma, Gypsy and Traveller people are included throughout this report, alongside other minority ethnic groups. The review examined five areas: mental health services; maternal and neonatal healthcare; digital inclusion and access to health services; genetic testing and genomic medicine studies; and the NHS workforce (ibid.).

Findings showed '…widespread ethnic inequalities in healthcare in the areas reviewed, as well as ethnic inequalities present for the NHS workforce' (ibid: 88). The report found common themes within the areas reviewed, and across the topics. Key findings were poor ethnicity data recording in NHS clinical records; a lack of infrastructure enabling data linkage at a national level; a lack of good quality national data disaggregated by ethnicity, age, gender and other relevant variables; a significant lack of good quality interpreting services; distrust of NHS services and professionals, stemming from experiences of racism; and a lack of high quality research studies, in which ethnicity is theorised appropriately and the mechanisms underpinning ethnic inequalities in healthcare are analysed (ibid.).

Many of these findings, which relate to minority ethnic communities across the UK, including Roma, Gypsy and Traveller groups, reflect the findings of both the main literature review of the present study, as well as its review of more recent literature. Significant difficulties for Roma people, in locating and accessing appropriate UK healthcare services, are also experienced by members of other minority ethnic groups (ibid.).

Subsequently, a more positive finding from the review of more recent literature was the online publication of a guide for health and care professionals, regarding the improvement of Roma health (UK Government website, 2022). This guidance, developed by the RSG in partnership with the Health and Wellbeing Alliance, offers practitioners advice regarding good practice, as well as practical actions to be taken when working with Roma people in the UK. More recently, the RSG (2023) has noted the need for UK policy response to the increasing number of Roma children being taken into care, in order to avoid replicating discriminatory practices in CEE countries. They praise a recent article (Berg and Inman, 2023) for highlighting this issue, whilst critiquing its focus on difficulties relating to the EUSS as the primary cause of the increase.

Roma resilience, agency, voice and self-representation

The examination of more recent literature shows the continuation of many of the issues identified in the main literature review. A lack of monitoring by ethnicity across the UK stills renders Roma people invisible to planners and to services. This, in turn, continues to produce a situation in which the needs of Roma community members are largely omitted from UK policy and strategy, in all areas of life, including health and well-being. In relation to migration, Martin et al. (2017: 2) state that: ‘It is evident that intra-EU migration has reinforced a range of pre-existing and widespread prejudices towards settled Roma communities’. Ongoing media portrayal and popular discourse across the whole of Europe, including the UK, have continued to associate Roma people with criminality, ‘work-shyness’ and deceitfulness, and with a popular perception of Roma within the EU as ‘benefit tourists’ (ibid: 2). Much of the governance of Roma migration in the UK has been focused on the management of Roma employment. This arose from political and media discourse, which both generated and exacerbated popular anxieties about the impact of free movement within the EU, prior to the Brexit referendum (Greenfields and Dagilyte, 2018; Nagy, 2018). Each of these examples has a negative impact on the well-being and health, including the mental health, of Roma people who have migrated to live in the UK (Zawacki and Ferranti, 2021; Orton et al. 2019; Zawacki, 2019; Smolinska-Poffley and Zawacki, 2017; RSG, 2012).

At the same time, however, the more recent literature also offers counter-narratives to this view of Roma migrants as a burden on the majority community, in the form of evidence of Roma resilience and agency, an increased presence of the voices of Roma people themselves in the literature, and alternative methods of research that place the Roma themselves at the heart of studies of their experiences, including those relating to health and well-being.

Roma resilience and agency

Within the ever-present context of prejudice and discrimination faced by Roma migrants to the UK, several more recent studies considered strategies of resilience and agency, employed by Roma people to avoid being identified as Roma, particularly in relation to the UK social security system (Nagy, 2018). Morell et al. (2018) note strategies of ‘invisibility’ or of identification with other migrants from CEE countries of origin, used by Roma people in the UK. Citing Clark (2014) and Grill (2012), they suggest that identification with non-Roma migrants ‘…acts as a counterbalance to widespread racialised negative discourse on Roma common in receiving countries’ (Morell et al., 2018: 3).

Smith (2018) extends this thinking about ethnicity to also include class. In a study looking at Slovakian Roma migrants in Chatham, Kent, he challenges homogenising categorisations of Roma migrants, based on ethnicity, which separate Roma people from other migrant populations and present them as qualitatively different. Smith discusses the shared experiences of the Slovakian Roma migrants within his study with those of other migrant groups and local working-class residents within the study locality, a poorer neighbourhood, where social structural processes and political decisions have increased inequality for residents of all social groups. Smith (ibid.) cites Wacquant's (2008) concept of 'advanced marginality' to portray the absorption of many Roma people into lower working-class economies and neighbourhoods. Smith also considers the differing generational experiences of older and young Roma migrants, whereby younger Roma people are more able to make relationships and identifications with younger members of other local groups, and to benefit from educational opportunities in the UK (ibid,).

Nagy (2018) considers the situation of Roma people who hide their ethnic background. Noting that they often migrate alone, tend to have relatively less deprived backgrounds than other Roma migrants, and share accommodation with non-Roma migrants from their countries of origin, she suggests that these practices of differentiation offer both identity management and internal bordering between different classes amongst the Roma. Hiding identity is a strategy employed for protection against anticipated stigmatisation and is used with the hope of increasing social inclusion. However, hiding identity may enable participation in a local economy but it does not necessarily prevent social exclusion in the wider host society (ibid.).

Nagy (ibid.) notes two employment paths linked to strategies of 'invisibility' used by Roma migrants. The first is to take up temporary unskilled jobs, which are often exploitative, as a means of remaining self-sustaining and avoiding welfare claims, and the second strategy is to become self-employed. However, whilst the aim in both cases is to avoid social 'othering' in the UK, in practice these tactics can, themselves, contribute to the social exclusion of Roma migrants (ibid.). Nagy (ibid: 14) states that: 'The decision to dissociate from social settings like a Roma diaspora epitomizes how participants perceive that they would be treated in London if they were identified. In turn this creates a wall of silence between these newcomers and the host society, increasing their social isolation, distrust in the host society and sustaining their situation of precarity'.

In his earlier work, Grill (2012: 1274) examines the wish of Roma people to escape from historical humiliation through migration, and the notion of 'going up' as '…moving upwards and forward and, in so doing, creating one's own future, thereby asserting one's own cultural agency to do so'. Grill (ibid.) explores Roma migration through the migrants' own concepts and practices, suggesting that this enables generalising and homogenising assumptions about

Roma migration to be critiqued. Grill (2017: 1) builds on his ethnographic studies to '…argue for more differentiated accounts of continuing and emerging forms of racialisation'. Placing the Slovak Roma migrants with whom he works firmly within the processes of developing categorisations, he examines how they renegotiate their position, both in relation to the social, economic and cultural structures encountered in the UK, and to the categories and structures experienced in Slovakia. Grill (ibid: 4) suggests that:

> Although the forms of domination and violence to which they have been exposed in the past left significant collective imprints on their social lives and bodily dispositions, they are also actively responding to these, and they too manufacture and perpetuate racial distinctions depending on their social locatedness.

Grill (ibid.) uses ethnography to explore the negotiation of identity among Slovak Roma migrating to and from the UK. Within this process, he includes aspects of negative interpellation, whereby Roma people come to internalise the external ascription of 'darkness' combined with 'Gypsyness' ascribed to them in Slovakia. Grill (ibid: 3) notes the initial hopes of the Roma migrants that this '…specific Slovak formation of racialised Gypsyness…' will no longer define them in the ethnically diverse UK city. He shows, however, that a wider range of factors can come to define 'Roma/Gypsies' as problematic, showing the contingency of classificatory categories (ibid: 17). Nevertheless, Grill's (2017, 2012) approach relocates Roma agency at the heart of their own experiences, thus offering hope for positive change in the future with a positive impact on Roma mental health and well-being.

The Roma voice in relation to health and well-being

The more recent studies examined showed an increase in publications by Roma authors, in relation to the representation of the Roma (Cohen, 2021; Franz, 2021; Balogh et al., 2019), alongside a recognition of the distance still to be travelled before Roma people achieve equity in each of the key areas of life, including health and well-being (Franz, 2021; Varga, 2020).

Matache, in Cohen (2021: 23) states:

> So far, most Roma policies at the national and European levels have focused on the oppressed, not on the oppressor, meaning these policies are creating the framework for equal access and individual human rights, but not ensuring justice. There is no interest in focusing on racism as the main problem that leads to structural inequalities.

The renewed EU Roma strategic framework (European Commission, 2020) does place tackling 'antigypsyism' and discrimination at the centre of its approach, but a true shift in thinking, away from a view of the Roma as a problem, rather than as a collectivity of people facing problems, has yet to take place (Cohen, 2021). In addition, Balogh et al. (2019) offer a range of critiques of the concept of 'antigypsyism', as part of the consultation process prior to publication of the renewed framework. They note a focus on Roma behaviour, as a problem to be addressed, rather than on structural factors generating and maintaining racism towards Roma people. They also comment on a lack of representation of critical Roma voices in EU consultation processes, including those relating to tackling 'antigypsyism', and suggest that the importance of an intersectional approach and the inclusion of women's issues is missing. Balogh et al. (ibid.) critique the term 'antigypsyism', since many Roma people experience the name 'Gypsy' as, itself, racist. They suggest the use of 'anti-Romani racism', as a more appropriate option (ibid.).

Despite this critique, the use of the term 'antigypsyism' has been retained within the new framework (European Commission, 2020). The purpose of the renewed framework is to improve the inclusion and participation of Roma people, yet there apparently remains a disjuncture between these Roma voices and the institutional processes of the EU. The EPHA (2020) points to the FRA (2019) recommendation, focusing on the role of public authorities at national and local levels in creating the conditions that can enable Roma participation in designing and implementing measures for social inclusion, and removing obstacles to this process. They stress the importance of genuine participation, rather than something tokenistic and superficial. In this context, the EPHA (2020) describes the creation of the Roma Health Network, set up in October 2020 to enable Roma voices to be heard at all levels, and to facilitate meaningful participation of Roma people in the design, implementation and monitoring of policy and strategy, focusing on health inequalities faced by Roma people across Europe. In the UK, Zawacki (2019) reports that the Roma participants in her study did not present themselves as victims. Rather, they wanted to tell their stories of having been wronged in their interactions with the UK health services, thus challenging common narratives. The study by Martin et al. (2017), in five locations in England and Scotland, also offers an example of the Roma voice in research countering negative stereotypes.

Alternative research methods

Matache, in Cohen (2021) believes that the stories of the Roma should be told by Roma people themselves. One such story is that of Roma people's health and well-being. In relation to research, the more recent literature included critique of assumptions underpinning research approaches and methods traditionally used in the field of Roma health and well-being (Bobakova, 2019; Orton et al., 2019). Orton et al. (ibid.) note the emergence of Roma health and well-being as a topic for both research and policy and offer a critique of earlier and current generic representations of 'the Roma' and of 'Roma health'. They suggest that existing representations, in research and in the media, have contributed to constructions of the health of Roma populations and to resulting actions within health systems and policy. In this view, the heterogeneity and diversity within and between Roma communities is overlooked, and they note that key policies to date '…have so far failed to make a difference to the health and wellbeing of European Roma populations' (ibid: 5).

Significantly, Orton et al. (ibid.) point out that most health inequalities research focuses on a limited time period and that much research carried out with Roma populations is cross-sectional. They suggest that adopting a historical perspective would enable the exploration of long-term health and well-being trends, as well as the intergenerational effects of past human rights abuses for Roma people in the present day. Orton et al. (ibid.) promote theory-driven approaches, particularly the use of intersectionality theory to explore how interrelated systems of power act on class, race, gender and other factors impacting on marginalised populations, comparisons with other groups in broadly similar social, economic and environmental conditions, and meaningful, equal participation of, and collaboration with, Roma populations when designing, carrying out and evaluating research relating to Roma people.

Bobakova (2019) notes remaining challenges for research, policy and practice, in relation to Roma health, including anti-Gypsyism, inclusion, participation, evaluation and resources. Bobakova (ibid.) also highlights the power relations that exist in the context of research, as well as the need for trust, and the importance of awareness of both conscious and unconscious attitudes towards Roma people. In addition, Bobakova (ibid.) and McFadden et al. (2018a) suggest a need for research into the effectiveness of interventions.

A systematic review of studies looking at Gypsy, Roma and Traveller access to, and engagement with, health services by McFadden et al. (ibid.) found barriers similar to those reported in the main literature review of the present study, including discrimination and negative attitudes of health service staff, cultural and language barriers, lack of knowledge regarding access to services and lack of understanding of medical jargon, fear, mistrust and financial barriers. Facilitating strategies reported were: specialist roles, which may be undertaken by community members; outreach and dedicated services, although sometimes these reinforced disengagement from mainstream services; raising health awareness; handheld records; cultural awareness training; and collaborative working between health services and community members.

This review (ibid.) examined studies from across Europe, including the UK, and from Canada, with the majority being from the UK. Whilst the number of studies from CEE countries was large and, presumably, related mainly to Roma people, the overall findings were not disaggregated between the different groups. McFadden et al. (ibid: 79) examined the quality of the 26 studies in their survey offering a detailed account of engagement strategies, concluding that '…study quality was generally poor across the different methodological components'. This suggests that, whilst Roma health and well-being is increasingly seen as a topic for investigation, methodology and, therefore, findings may need to be viewed critically.

Echoing Orton et al. (2019), McFadden et al. (2018a) note that experiences of discrimination and lack of cultural awareness within healthcare services have been reported in studies looking at other minority ethnic groups, whilst acknowledging the significant prejudice and discrimination experienced by Roma people across all areas of their lives. They note the inclusion of the voices of Roma people in some studies but their lack in others and suggest that certain engagement strategies may act to discourage the use of mainstream services, thereby becoming counterproductive. In a similar vein, they also critique cultural awareness training, which may be helpful but risks reproducing stereotypes and failing to include the multiple identities and diverse social realities experienced by Gypsy, Roma and Traveller people (ibid.). A study by McFadden et al. (2018b), looking at enhancing the trust of Gypsy, Roma and Traveller people, suggests that maternity and early years' health services and dental services provide exemplars of good practice.

Grill (2017, 2012), privileges ethnography, to show how intensive, prolonged engagement with members of Roma communities can shine a light on the complexity and detail of constantly shifting social and regional particularities and embodied dispositions. Grill (2017: 5) critiques more one-dimensional accounts of '…how Roma/Gypsies are produced as particular subjects in relation to discursive transformations and differential forms of inclusion/exclusion'. In doing so, he repositions agency vis-à-vis structure in debates about both categorisations applied to Roma and their own ability to respond to these categorisations.

Similarly, Smith (2018) challenges the 'myopia' within Romani Studies, whereby Romani people are studied and written about from a perspective that views them as 'unique' and qualitatively 'different' from members of other communities. The Roma migrants in Smith's study are integrated into Wacquant's (2008) 'advanced marginality', thereby joining other disadvantaged communities, defined by social class, and by age, as well as by ethnicity. Roma migrants are, thus, repositioned away from homogenising categories and into more complex, hybrid groups: Vertovec's (2006) 'hyper-diversity', cited by Smith (2018). Smith (ibid: 188) cites Tremlett (2014) who '…cautions against the unreflexive use of ethnicity as the basis of individual and collective identity as this apportions groups into discrete spheres that rarely exist in reality'. One outcome of such an approach is that this focus on 'difference' between Roma people and others results in the merging of an idea of Roma culture with that of poverty (ibid.). As Orton et al. (2019: 6) state:

> 'What sets the Roma apart is the way in which the health experiences of distinct and heterogeneous populations in different settings and circumstances have been conflated and singled out in policy, the media, health care systems and in research'.

2.7.2 Post-migration experiences

Governance of Roma migration and its impact on health and well-being

Among the more recent studies examined, several addressed aspects of ongoing marginalisation and social exclusion of Roma migrants to the UK (Humphris, 2019; Greenfields and Dagilyte, 2018; Morell et al., 2018; Nagy, 2018). Following the end of the Soviet Union in 1991 and the transition of CEE countries into the market-based economy, Roma people living in these countries became increasingly disadvantaged, due to their limited skills base for employment and their experiences of overt discrimination (Morell et al., 2018). However, what was, in fact, a profound economic and social change impacting negatively on the life chances of members of Roma communities became interpreted as a problem of Roma culture (ibid.).

After the accession to the EU of the A8 countries in 2004 and, more particularly, the A2 countries, Bulgaria and Romania, in 2007, the positioning of Roma people within post-Soviet Central and Eastern Europe, together with the operation of western European state policies, served to limit the opportunities of Roma migrants, despite their theoretical equal right to free movement within the EU (Official Journal of the European Union, 2004/58/EC). Morell et al. (2018) offer an overview of the governance of Roma migrations within the EU, in the context of the difficult relationship between a neoliberal market economy and regional and economic inequalities among EU member states. They note the significance of the governance of Roma migration from Central and Eastern Europe by receiving states, and its impact on the abilities of Roma migrants to access welfare benefits and services, and to secure employment and adequate housing (ibid.). The precarity of the living conditions of Roma migrants, framed by ongoing discrimination, both in their countries of origin and in receiving countries following migration, carries obvious negative implications for their health and well-being.

Against a backdrop of increasingly hostile media and political rhetoric, Roma migrants became '…singled out in terms of policy, media and political discourses and practices as a key example of all that is dysfunctional about the EU and its core principle of freedom of movement' (ibid: 3). In 2013-2014, changes to the UK welfare regime, designed to make access to welfare benefits more difficult for migrants from other EU countries, served to place migrant Roma under particular scrutiny (Greenfields and Dagilyte, 2018). These changes, notably, coincided with the lifting of restrictions on work for migrants from Bulgaria and Romania. Roma people, in this context, were associated with stereotypes regarding welfare dependence and cheap labour, and this narrative fed into the anti-migration discourses that were a key element of the campaign for the UK to leave the EU (Morell et al., 2018; Nagy, 2018).

Nagy (2018) and Greenfields and Dagilyte (2018) suggest ways in which Roma migrants to the UK, as well as to other long-standing EU member countries, faced hurdles to be overcome in addition to those pertaining to the legal requirements of the EU Free Movement Directive (Official Journal of the European Union, 2004/58/EC). Greenfields and Dagilyte (2018: 84) ask, '…whether multi-factorial social exclusion, both pre and post migration, places Roma migrants in a situation of unique disadvantage, leaving them particularly vulnerable to negative welfare governance and at risk of expulsion'.

The outcomes of their research showed no evidence that Roma migrants were drawn to the UK by the idea of easily accessible welfare benefits, despite this being the narrative of racialised media and political discourses (ibid.). Echoing the findings of Martin et al. (2017), their Roma respondents stressed the value of work to both their self-esteem and their ambitions to create better lives for themselves and their families. However, many Roma migrants, especially on first arrival in the UK, took up '…low paid, often "grey-market"/cash in hand work…' (Greenfields and Dagilyte, 2018: 90). As a result, in-work low-pay 'top-up' welfare benefits and support for housing costs were sought, but barriers to these benefits were encountered, particularly after the changes to the UK welfare system in 2014 (ibid.). Language barriers and difficulties with literacy, together with complex requirements for documentary evidence of entitlement, served to make this process extremely difficult or impossible for many Roma migrants to the UK. Lack of knowledge about UK welfare entitlements and limited access to agencies supporting Roma people also contributed to this difficult situation (ibid.).

In addition, Greenfields and Dagilyte cite Stuart Hall's (2000) notion of 'inferential racism', to describe the attitude of many officials encountering Roma clients, who had no knowledge of Roma culture or history, or empathy with Roma people, and who were influenced by the popular negative stereotypes of the Roma increasingly being portrayed through the UK media at this time (ibid.). As a result, Greenfields and Dagilyte (ibid: 94) posit '…practices of tacit bordering and policing by state agencies, which operate[d] to "encourage" return migration of EU Roma citizens to their home countries, in contradiction to EU law which [continued] to apply throughout the transitional period before Brexit'.

Nagy (2018) also examines processes of securitisation within EU receiving countries, in relation to migration, particularly regarding Roma people from Central and Eastern Europe. Nagy looks at processes of social exclusion of Roma migrants, based on their economic opportunities and strategies rather than directly on racialising processes. Again, the basic legislative requirements are supplemented for EU migrants, in particular Roma people, by additional obstacles to accessing welfare benefits. Using primary research in four Central and East European countries, and the UK, Nagy (ibid.) shows how a wish to avoid bureaucratic surveillance and discrimination leads many Roma migrants to use economic strategies that allow them to stay under the radar of administrative control measures. However, discourses associated with a perceived threat from non-EU migrants have also been applied to EU Roma migrants, with the result that the distinction between welfare and crime control measures has become blurred (ibid.).

Nagy (ibid: 4) suggests that '…welfare provisions have turned into the new geopolitical incentives of social sorting, applied by governments who use digitalized control techniques to guard against mobile immigrant groups.' Describing the growing privatisation of public sector activities, Nagy (ibid.) shows how neoliberal values have been transposed from the business sector, incorporating incentives that police, rather than support, welfare claimants. For Roma and other EU migrants who wish to avoid the gaze of the state, merely being in employment is insufficient to escape what Nagy (ibid: 6) describes as 'a moral component' of judgement.

In this view, individuals are also judged according to their moral worth, a key measure of which is the perceived value of their economic activity. In order to gain neoliberal state recognition, and social citizenship, more is now required than abiding by the formal legal rights and duties (ibid.). Nagy argues that neoliberalism and communitarianism combine to socially exclude Roma migrants who seek self-sustainable and entrepreneurial employment, which enables them to hide their ethnic identity and to avoid state surveillance but which, at the same time, is regarded by the host society majority as a means of tax avoidance or is a stigmatised activity, such as scrap dealing. This social 'othering' exposes Roma migrants to a continuation of the prejudice and discrimination that they migrated to escape and prevents their full acceptance within the receiving countries (ibid.). Once again, Roma people experience circumstances that will inevitably have a negative impact not only on their material well-being but, also, on their emotional and physical well-being.

Further insights into neoliberal practices of UK state governance of Roma migrants are provided by Rachel Humphris (2019). In a review of her book, Clarke (2020) describes Humphris's ethnographic work with Roma women in Luton, who had migrated from Romania. The book explores home visiting by front line state workers, with a focus on Roma children's well-being and development, but with a sub-text whereby the home becomes the site of judgements regarding the 'deservingness' of the children's mothers. Through this process, 'sorting' of Roma families takes place, with some receiving support to access welfare benefits or to make applications towards official citizenship, while others are deemed 'undeserving' (ibid.).

Again, the idea of moral neoliberalism comes into play, turning around the emotionally charged topic of child welfare, while judgements about Roma migrants that go beyond formal legal requirements and into a zone of morality are made (ibid.). Ultimately, all the mechanisms of governance of Roma migrants described in this section contribute to their success or failure in establishing themselves as both legally and morally entitled to a healthy and emotionally satisfying new life in the UK. In a wider UK context, Monbiot (2022) discusses the Police, Crime, Sentencing and Courts Bill, within which trespass becomes a criminal, rather than a civil, offence. Among a broad swathe of seemingly anti-democratic measures, the lifestyle of nomadic members of Romani and Traveller communities becomes criminalised, due to a lack of legally recognised stopping places. It is in the context of public discourse surrounding this legislation that Roma and other migrants, as well as asylum seekers, seek to be made welcome in the UK. Monbiot (ibid: 4) links current legislation, criminalising nomadism, to the centuries-long persecution of the Romani people, as well as to British historical control of the poor: ‘The new authoritarianism meshes with a very old one, that harks back to an imagined world in which the peasants could be neatly divided into villeins (good) and vagrants (bad), where everyone knew their place, geographically and socially’.

Post-Brexit experiences

Following the outcome of the 2016 Brexit referendum, in which the UK population voted by a narrow margin to leave the EU, the situation of migrants from all EU countries in London and across the UK, especially Roma people, became immediately more precarious. Members of Roma communities faced uncertainty regarding their future legal status, concerns about hate crime, and the loss of EU funding for supporting services (Morris, 2016). Zawacki (2018) notes the strain on the sense of security of Roma people, who had experienced the diversity of the UK as a place in which the stigmatisation of Roma identity was less overt than that experienced in their countries of origin. Alongside the negative impact on mental well-being of persistent racist discourses surrounding EU free movement within the UK tabloid media (Greenfields and Dagilyte, 2018), and overt hostility expressed around the time of the Brexit referendum (RSG, 2020), the most urgent problem faced by Roma people in the UK related to the European Union Settlement Scheme (EUSS) (RSG, 2021a, 2020; Stalford and Humphreys, 2020; Perraudin, 2018; Zawacki, 2018).

With a deadline of the 30th June 2021, the EUSS was described by the then Home Secretary as the process of answering ‘… “three simple questions” in an online form to continue living in the UK once it has left the EU’ (Perraudin, 2018). These questions referred to proof of identity, proof of having no convictions, and proof of current residency in the UK (ibid.). However, Roma-led NGOs, other NGOs supporting Roma people, and the small number of local authorities providing direct support to their Roma communities noted significant barriers to be overcome, if Roma migrants from EU countries were to achieve settled status under the scheme (RSG, 2021a, 2020). The RSG (2020: 4) stated that: ‘Overall, the evidence in this report [ibid.] suggests that the EUSS is a plausible system for granting UK residency, but that there are substantial barriers to Roma people gaining knowledge of and access to this system’.

Barriers identified included lack of awareness of the need to apply; lack of access to trusted sources of information; lack of access to technology; low educational levels and low levels of functional and digital literacy; language barriers; lack of valid ID cards or proof of five years’ residence – often due to being employed in the informal economy or to unstable housing conditions; and reluctance to send ID cards to the Home Office (RSG, 2021a, 2020; Perraudin, 2018; Sumption, 2018; Zawacki, 2018).

In addition, the RSG (2021a) noted barriers caused or worsened by the Covid-19 pandemic. These included a lack of face-to-face support; difficulty in accessing ID documents, due to reduced staffing at embassies; and a break in the continuity of UK residence for Roma people who returned to their country of origin. Absence from the UK would affect ability to obtain settled status, a fact that Roma people may not be aware of. Some, also, were unable to return to their countries of origin, in order to renew passports, due to lockdown travel restrictions (ibid.).

A range of groups was identified as being at risk of failing to achieve settled status under the EUSS, many of which were likely to include members of Roma communities living in the UK (RSG, 2021a, 2020; Stalford and Humphreys, 2020; Sumption, 2018; Zawacki, 2018). In an article looking at the EUSS in relation to all EU migrants living in the UK, Sumption (2018) noted that most of this population was young and well-educated and should have little difficulty completing the online application. For many of those affected, tax records and other documentary evidence would have been held previously by the UK government and would not have needed to be provided again. Nevertheless, Sumption (ibid.) identified those unaware of the need to apply or without the ability to do so, including children, particularly children in care; long-term residents who may not realise they are affected; those fearing rejection or believing themselves to be ineligible; those without ID, passports or bank accounts; people with mental health problems; and victims of domestic abuse, who might rely on a partner to provide evidence. Sumption (ibid.) also suggested that factors such as age and disability could influence the outcome of the process for some, noting that around 56,000 EU citizens in the UK in 2017 were aged over seventy-five years.

The RSG, (2020), focusing on the needs of Roma communities in the UK, also noted the vulnerability in this situation of elderly people, as well as women, including those providing childcare, children, children in care and care leavers, rough sleepers, and pre-settled status holders. In addition, Zawacki (2018: 3) draws attention to the risks for those who may have overseas criminal records, registered in their countries of origin: 'Roma in Eastern Europe are often subject to routine and unjust criminalization, yet it is unlikely that Home Office assessments of criminality will take into account the social context of Roma applicants' criminal records.'

The ways in which Roma children in the UK have been particularly affected by the difficulties involved in making applications for settlement through the EUSS were considered by Stalford and Humphreys (2020). They noted the absence of Roma children from public debates and initiatives aimed at children in the context of the EUSS, most of which focused only on looked after children. Stalford and Humphreys (ibid.) pointed to the necessity of engaging with Roma children about the EUSS process since, despite official assumptions that parents would manage their children's applications, for many Roma families it was the children who had the language, literacy and digital skills needed to understand the requirements and to ensure that applications were made by the 30th of June 2021 deadline.

Data collected in March 2020 suggested that less than 50% of all children eligible under the EUSS had, in fact, registered, and data relating to the registration of Roma people did not exist (ibid.). It was impossible to ascertain, with any degree of certainty, the number of Roma children who had not made an application for settled or pre-settled status, and who remained at risk of poverty and possible deportation. Zawacki (2018) noted that it was unclear as to what would happen to those who missed the deadline for applications for settled status. Data collected by the RSG (2020) estimated a UK Roma population of more than 200,000 eligible claimants; of these, around 2.6% had been supported to register, against Home Office statistics suggesting that approximately 91% of those eligible overall had made a registration (Stalford and Humphreys, 2020). Stalford and Humphreys (ibid: 17) noted '…the potential for the EUSS to operate in an indirectly discriminatory way insofar as it is so much more difficult for Roma people to access the scheme and meet the eligibility requirements than for other EEA migrants.'

Support and advice for Roma people living in the UK, in relation to the EUSS process, has been limited and has relied on the efforts of community organisations, individual activists and local authority departments in areas with significant Roma populations (RSG, 2021a, 2020). Alongside a lack of monitoring by ethnicity of Roma people, a lack of national or UK-wide strategy regarding Roma inclusion and improvements in all aspects of their lives persists. In the wake of the Brexit vote, EU funding requiring member states to put in place policies and practices aiming to improve the life chances of the Roma, in the areas of education, employment, health and housing, together with a focus on combatting discrimination, will no longer be available (Stalford and Humphreys, 2020; Morris, 2016).

The RSG (2020), though, do note more effective engagement between NGOs, Roma communities and public services, as a result of the demand for EUSS support from Roma community members. They emphasise the importance for Roma people of trust-based relationships in both this context, and more broadly in relation to support in all areas of their lives. Recommendations include the issuing of physical evidence of EUSS status, based on Roma people's anxieties regarding digital only evidence, as well as the difficulties for many in accessing this evidence and of maintaining an up-to-date online account. It is also recommended that the Government send reminders to pre-settled status holders, in good time for update applications to be made. In addition, schools, employers and sub-contractors should be advised regarding their responsibilities towards EU citizens, including Roma people, post-Brexit (ibid.).

Post-pandemic experiences

Not only did Roma people in the UK face a long period of anxiety following the Brexit decision (ibid.), but they also faced increased barriers to successful EUSS application, as a result of the Covid-19 pandemic (RSG, 2021a). During the period between the launch of the EUSS on the 29th March 2019 and the 30th June 2021 deadline for applications, a greater threat to Roma health and well-being emerged in the form of the SARS-CoV-2 global pandemic. Roma people throughout Europe now faced a combination of health risks, economic deprivation and greater stigmatisation (Walker, 2020). For Roma migrants in the UK, these two events became entangled, resulting in a worsening of their situation and their prospects.

Writing early in the pandemic period, Matache and Bhabha (2020: 379) describe '…a frightening escalation of populist and racist voices intent on blaming the Roma community for this pandemic.' Despite requests from EU agencies and the requirements of international and European human rights treaties, Roma people became constructed as a threat to the health and safety of mainstream populations in CEE countries (Korunovska and Jovanovic, 2020; Matache and Bhabha, 2020). Zawacki (2020: 2) notes that: 'Roma – like other marginalised, underserved groups – are scapegoated as transmitters of illness, as unable to adhere to physical distancing guidance and as undeserving of support'. Across Europe, derogatory media narratives focused particularly on Roma who had recently returned from other countries (ibid.). These very harsh attitudes towards members of Roma communities in the context of the Covid-19 pandemic did, however, lead to some instances of people challenging the stereotypes, as well as indications that the pandemic had alerted authorities to their obligation to help Roma people, rather than to blame them (Walker, 2020).

Korunovska and Jovanovic (2020), writing for the OSF, note that state provided social assistance during the pandemic was not accessible to those returning from Western Europe to their countries of origin, or to those who had made a living working in the informal economy. Lack of healthcare insurance for Roma people in CEE countries paralleled the experiences of ethnicised groups in the USA, where: 'Black and Latinx [sic] communities have shown disproportionate rates of infection and death from COVID-19' (Zawacki, 2020: 4). Matache and Bhabha (2020) point out the impact of pre-existing structural inequalities on the health and well-being risks to European Roma community members during the pandemic, as a result of the willful neglect of Roma human rights entitlements over many years.

The exacerbation of pre-existing social exclusion and health inequalities, in particular a high burden of chronic disease, led to Roma communities being disproportionately impacted by the Covid-19 pandemic (Pollak, 2021). Overcrowding or homelessness also contributed to these difficulties (ibid.), as did a lack of savings and a need for assistance in obtaining food (Korunovska and Jovanovic, 2020). Roma children were also disadvantaged when digital illiteracy and a lack of technological devices contributed to their exclusion from remote learning programmes (ibid.). The RSG (2021b) note that this situation has added to already existing educational disadvantages for Roma children across the UK, although some locally focused efforts had been made to provide hard copy materials and digital equipment to Gypsy, Roma and Traveller children.

Similarly, in the UK, the RSG (ibid.) noted the disparity of health outcomes for different groups, the association between ethnicity and different levels of risk and health outcomes, and the high levels of chronic disease among older Roma people. The lack of a focused approach to the needs of Roma communities during the pandemic resulted in considerable variation among the responses of local authorities, at a time when Roma people were experiencing increased need alongside limited access to their usual support services. Roma people in the UK faced language barriers, financial difficulties, difficulties in obtaining food, and digital exclusion during a period of greater use of online services (ibid.). It was important for Roma community members that information should be accessed from trusted sources, with a range of approaches being adapted to their needs, such as videos and written materials produced in community languages, including Romanes (ibid.). In this context, the RSG (ibid.) note the role of Roma community champions, whereby Roma people, often initially volunteers, are developed to become community workers and advocates, supporting members of their own communities. They give the example of a community centre in Newport, Wales '…where Roma women can volunteer and move into a job' (ibid: 5). An example in Bristol, whereby community workers from other migrant backgrounds supported Roma people, was also successful, due to a shared experience of migration to the UK. In all cases, the key task was to provide holistic support, and effective signposting to wider services, so that Roma people became aware of the range of services available to them (ibid.).

Across the UK, NGOs, as well as a few local authorities, developed flexible responses to the changing needs of Roma migrants during the pandemic, and these have led to some more permanent services and strategies for supporting Roma communities in the UK, although these are not by any means UK-wide (RSG, 2021b; Hetherington et al., 2020). Whilst local authority support has been limited and reliant on local need and interest, the Covid-19 pandemic has shown that a time of crisis can provide the motivation for strategic change. The RSG (2021b) also recommends efforts at a national level to overcome the digital, linguistic and cultural barriers faced by Roma people in the UK, in relation to accessing public services, including healthcare services.

The long-term effects on Roma community members in London and the wider UK of the combination of Brexit and the Covid-19 pandemic are not yet clear (RSG, 2021a). However, there can be no doubt that this extremely difficult period has been stressful and uncertain for UK Roma migrants, with significant implications for their health and well-being.

2.8 Summary

Main literature review

A wide-ranging literature of many types was identified. This included European and academic reports, as well as studies undertaken by small organisations such as NGOs. Information regarding the health and well-being of Roma people in the UK was sometimes contained within Europe-wide research. There were few studies focussing specifically on Roma health and well-being in the UK, and these tended to be very locally based. In much of the UK literature, the health and well-being of Roma people was addressed alongside that of Romanichal Gypsies and members of other Traveller groups. Existing literature reviews on the topic of Roma health were old and offered very little information regarding the situation in the UK.

Within the literature looking at Roma health and well-being in the UK and more widely, the evidence base for some assertions was not always clear. Larger European studies, or academic research, were likely to be more reliable, but the European studies, too, cited each other regarding, for example, Roma life expectancy, without having a clear source. Although Roma people across Europe clearly faced many health and well-being issues, there appeared to be a danger of myth making, in relation to Roma health and well-being.

Studies examining Roma health and well-being in the UK were drawn from within this overall broad literature and fourteen topics were identified and analysed, with the findings being organised into three overarching themes: health service limitations; perception of a weak policy response; and social and cultural determinants of Roma health and well-being.

Through examining these themes, it was possible to identify limitations within the UK health service, including practical barriers such as a lack of interpreters and limited information about healthcare services, and the failure to monitor Roma ethnicity. Limitations linked to prejudiced views were also identified, together with a lack of understanding on the part of service providers, regarding cultural issues affecting Roma people's ability to access health and well-being services. NHS provision is guided by national policy. However, there was no strategic healthcare policy in the UK with regard to the needs of Roma community members, despite the EU requirement for a National Roma Integration Strategy (NRIS), prior to the UK's departure from the EU.

The implications of this policy weakness suggested a reciprocal relationship, whereby there is an absence of research, which could contribute to policy development, together with a lack of strategic policy, which would generate the need for further research. Strategic policy, underpinned by planned research, would contribute to a consistent UK-wide approach to the health and well-being needs of Roma people. The studies examined also highlighted the impact of both social and cultural factors on Roma health and well-being, although there was limited critique of the interaction between these. Although the literature presented them as equally important, it was not clear whether the cultural issues would remain as significant barriers if the structural factors, including discrimination, poverty and lack of strategy, were to be addressed.

A critical analysis was undertaken of the methodologies underpinning the UK studies examined in the main literature review, where these were stated. In many cases, the methodological assumptions behind the studies were not made explicit, perhaps weakening the evidence presented. Themes and trends within the existing literature were considered, together with possible biases and limitations. There was little discussion regarding narratives and discourses surrounding Roma health and well-being within the UK literature in the main review, or of representations and self-representations of the Roma in the context of health and well-being, and the voices and views of Roma people themselves were absent in many cases. Carrying out this analysis allowed the present researcher to identify a gap in the research picture, thereby leading to the design of the present study, using concepts problematised by post-structuralist thinking. The use of these concepts is discussed in Chapter three.

More recent literature

The more recent literature examined showed slow progress, in terms of overall improvements in Roma integration across Europe. In relation to closing the gap between the health and well-being experiences of Roma people and those of the general population, the risk of poverty had reduced, with self-perceived health status of Roma improving. Access to medical coverage, however, remains limited (European Commission, 2020).

A key limiting factor regarding improvements in all aspects of Roma people’s lives is political and media discourse, creating and sustaining prejudicial and discriminatory attitudes towards Roma communities. Despite a professed wish to tackle anti-Gypsyism in the renewed EU Roma strategic framework (ibid.), European and national policy still tends to focus on Roma people as the source of their own problems. An ongoing view of Roma culture as synonymous with poverty (Smith, 2018) and of Roma cultural behaviour as problematic prevents structural factors, including racism and discrimination, being identified as causes of exclusion and poor outcomes (Cohen, 2021; Kühlbrandt 2019). The lack of data about Roma health and the scarcity of coherent strategy identified in the main literature review remain (RSG, 2022, 2021b; Hetherington et al., 2020), and Roma people continue to be framed as a threat to public health (Korunovska and Jovanovic, 2020; Matache and Bhabha, 2020; Zawacki, 2020). The chronic disease burden among Roma people in Ireland described by Pollak (2021) similarly reflects the findings of the earlier literature.

In the UK, no longer subject to EU legislation, there is no significant strategic approach to the needs of Roma people, including those relating to their health and well-being, and the UK Gypsy, Roma and Traveller National Strategy, due to commence in early 2020 (Ministry of Housing, Communities and Local Government and Lord Bourne, 2019) remains underdeveloped (RSG, 2022). The issuing of online guidance for UK health and care staff working with Roma people was, however, a positive development (UK Government website, 2022). Issues regarding the governance of Roma migration prior to Brexit, together with the uncertainties regarding settled status following the referendum, created a very precarious environment for Roma migrants to the UK (RSG, 2021a, 2021b, 2020), with the impact of the Covid-19 pandemic compounding pre-existing social, material, and health and well-being inequalities for members of Roma communities across the whole of Europe. Among ongoing health and well-being difficulties, Roma mental health remains a key aspect of well-being, but one which continues to be under-researched (Zawacki and Ferranti, 2021).

Nevertheless, the more recent literature showed an increased presence of the voices of Roma people, as research participants and as authors or researchers, There was also evidence of resilience and agency on the part of Roma migrants, in response to their post-migration experiences. This offered a picture of counter-narrative to the popular view of Roma migrants as a burden on majority communities.

Across the recent literature, there was a strong thread promoting the use of intersectional theory (Crenshaw, 1991, 1989), in particular regarding Roma women’s experiences. Critique also emerged of a consensus narrative, within policy and research, in relation to the representation of Roma people as ‘Other’, or as qualitatively different and always in need of intervention, and of Roma culture and cultural behaviour as central to difficulties experienced by Roma people. The resulting production of knowledge was, therefore, questioned, although the studies examined did not describe their own epistemological positions in depth. Many of the experiences of inequality reported by Roma people, in relation to accessing healthcare services in the UK, were also reported by members of other minority ethnic groups. Overall, the review of more recent literature suggested a need for ongoing analysis of discourse and narrative relating to Roma representation and self-representation, and a consideration of alternative narratives, research methods and opportunities for Roma people to speak about and address their own health and well-being experiences.

ANALYTIC CONCEPTS THROUGH A POST-STRUCTURALIST LENS

3.1 Introduction

The purpose of Chapter three is to outline the theoretical framework, drawing on poststructuralist theory, used to approach the research for the present study and to inform the analysis of the resulting data. The findings of the literature review, as well as the historical and contemporary context outlined in Chapter one, presented questions about ways in which Roma people are represented and constructed, how the opportunity for Roma agency is created or inhibited at different levels, and how these factors impact on understandings of their health and well-being experiences in the UK.

A wide range of differing constructions of Roma people have relevance for the present study. These include understandings within the EU, within the UK NHS, by the voluntary sector, by academics, by the media, by other Gypsies and Travellers, and by Roma people themselves, individually and in groups. Differing constructions of the Roma – as a minority ethnic community (European Commission, 2017, 2011; Matras, 2004; Gheorghe, 1997), or not (Willems, 1997; Okely, 1983); as marginalised (NICE, November 2018); as reluctant to conform with the expectations of mainstream society (France 24, 2016; Gilligan, 2015; O'Neill, 2008); or positioned between development need and security threat (van Baar, 2018); all presented themselves for consideration in relation to the health and well-being outcomes of Roma individuals and groups.

The present researcher was interested in how constructions of Roma people within Europe interacted with both their own relationship to their health and well-being and, also, the views of Roma health and well-being held by healthcare professionals and others. The weak governmental response to the EU requirement for an NRIS, the lack of NHS monitoring by ethnicity, and the efforts made by voluntary sector organisations suggested complex readings of the positioning of Roma people in the UK, in relation to their health and well-being. The Roma have been constructed historically, and continue to be constructed, in ways that continually marginalise them (van Baar, 2018, 2011a; Hancock, 2002; Fraser, 1995). The fact that Roma people have been represented largely by non-Romanies in the public domain has already been noted (Greenfields, 2013; Hancock, 2002), along with the ambiguous constructions of Roma people as, on the one hand, a homogeneous minority ethnic group and, on the other, as marginalised outsiders occupying an anomalous and deviant position.

The present researcher agreed with McVeigh's (1997) theorising of the residual threat posed to sedentary society by the current or previous nomadic status of Gypsies, Roma and Travellers, and this view fitted well with van Baar's (2018) understanding of the Roma as positioned in the nexus between development and security within the EU and Europe as a whole.

A reading of the work of van Baar (2011a), in which he uses Michel Foucault's (2004) concept of governmentality to examine the ways in which the Roma have been constructed as a transnational European minority, following the end of the Soviet Union in 1991, suggested the use of a framework based on concepts considered from a post-structuralist perspective, through which to examine the experiences of migrant Roma people living in the UK, in relation to their health and well-being. Van Baar (2011a) discusses the EU approach to Roma inclusion, which aims to bring Roma people into full and active citizenship of member states.

Van Baar (2011a: 28) defines neither himself nor Foucault as a 'post-structuralist' theorist, but notes the contribution of Foucault's neologism, governmentality, 'to at least three important discussions in late-twentieth and early twenty-first-century post-structuralist social and political thought'. These aspects relate to changes in perceptions of the state in the context of globalisation; the increasing focus of governmental power 'at the intersection of individual bodies of persons and the collective body of a population' (ibid: 28); and debates about the relationship between structure and agency, and power and resistance, looking beyond binary oppositions (ibid.). Van Baar (ibid.) looks at the governance of all aspects of Roma lives in Europe. However, the Foucauldian theoretical concepts he employs, of governmentality and bio-power, have a direct and specific relationship with the management of health and well-being, and the control of the bodies and minds of all European citizens, including the Roma in Europe. Foucault's concepts regarding governance apply to the perception of the European Roma as a collectivity that both threatens security, and requires developmental support (van Baar, 2018) and, more specifically, to the management of health and well-being. For these reasons, a post-structuralist theoretical approach seemed appropriate for the present study.

Within this overall context and based on the literature examined in Chapters one and two, the present study uses concepts of voice, culture, identity, agency and nomadism, problematised by post-structuralist thinking, to critically examine the study's empirical findings in relation to this literature. These concepts were selected to consider the positionings of Roma people, individually and in groups, in relation to their health and well-being, processes of marginalisation as these relate to Roma health and well-being, and opportunities for agency and resistance on the part of Roma people, in the context of health and well-being. In the following section, post-structuralism as a broad stream of theoretical thinking is discussed, together with the significance of post-structuralism for Roma health and well-being, in the context of the work of Michel Foucault and Huub van Baar. This is followed by a consideration of post-structuralist ontology and epistemology, particularly in the context of social research. The final section of this chapter examines conceptualisations of the concepts used to problematise the study's findings.

3.2 Post-structuralism

McDonnell et al. (2009: 90) describe post-structuralism as 'an intellectual movement rather than a discreet [sic] body of theory, which rejects what is popularly referred to as "grand theory" (totalizing theories of society based on universal concepts)'. Post-structuralist writers challenge the concepts of universal and objective truth claims and stress the socially constructed and historically specific nature of all knowledge (ibid.). The term post-structuralism refers to the work of a wide range of theorists, who have been interested in the ways in which human beings make and reproduce meanings about the world, and whose thinking also challenged earlier structuralist theory (Belsey, 2002). Belsey (ibid: 5) states:

> On the one hand, poststructuralists affirm, consciousness is not the origin of the language we speak and the images we recognise, so much as the product of the meanings we learn and reproduce. On the other hand, communication changes all the time, with or without intervention from us, and we can choose to intervene with a view to altering the meanings - which is to say the norms and values - our culture takes for granted.

On the surface, post-structuralism appears to resemble social constructionism, in which '[t]he sociology of knowledge understands human reality as socially constructed reality' (Berger and Luckmann, 1971: 210). Social constructionism, however, differs profoundly from post-structuralism in its focus on a dialectical relationship between social reality and individual existence in history, and its understanding that '[l]anguage originates in and has its primary reference to everyday life' (ibid: 53). Language, in social constructionism, is seen as '[being] capable not only of constructing symbols that are highly abstracted from everyday experience, but also of "bringing back" these symbols and appresenting them as objectively real elements in everyday life' (ibid: 55). In other words, meaning resides in experience, which language turns into symbols that can be used to communicate experience. In post-structuralism, on the other hand, the role of language is foundational in the creation of meaning (Belsey, 2002).

In terms of the rejection of objective truth claims, Ritchie et al. (2014) do not discuss post-structuralism, but they contrast positivist and post-positivist epistemological positions with those of interpretivism and constructionism. They note critiques of scientific positivism and post-positivism, in which an observer or researcher was believed to be able to take up a position of detached objectivity in relation to that which they observed or studied (ibid.). Positivist beliefs were based upon the ideas that knowledge is foundational, and that reality can be known accurately, using the methods of the natural sciences to study both the natural world and the human social world, without the researcher affecting whatever is studied (ibid.). Post-positivist theories, likewise, assume that reality is unaffected by the research process, but that reality can only be known approximately, and that knowledge is, therefore, provisional. Post-positivist theory also sees the methods of natural science as appropriate for studying the human social world (ibid.).

The roots of the challenges to positivist and post-positivist theory lay in a questioning of the supremacy of Enlightenment rationalism, in relation to capitalism and modernity, beginning with the thinking of Max Weber and members of the Frankfurt School (Callinicos, 2007). Rationality was originally seen as freeing from earlier religious and other doctrines, but became, itself, a new doctrine, with its certainty about the objectivity of the modern scientific method. The inter-war disillusionment of the German sociologists was followed by similar concerns amongst French thinkers after the second world war. Both capitalism and Marxism, in the form of Stalinism, had led to terrible outcomes, which put into question earlier beliefs in Marxist theory as a solution to the problems of capitalism (ibid.) Callinicos notes that many theorists began to pursue a third alternative, in which sociology could be framed by historical transformation rather than by social stability (ibid.). Callinicos (ibid: 262) refers to 'The Civilizing Process' by Norbert Elias (1939):

> Elias offers a new slant on the process of rationalization which preoccupied Weber. He seeks systematically to connect the development of centralized bureaucratic states in the early modern era to the gradual transformation of personal behaviour and psychic structures that he traced in European court society in particular.

The collection of ideas known as post-structuralism developed, largely in twentieth century post-war France, from the work of Ferdinand de Saussure (1977), from whose analysis of linguistics one of the core concepts of post-structuralism was derived by Jacques Derrida (1976). The work of de Saussure was founded on the principle of the primacy of speech, with writing being a secondary means of transcribing oral exchange (Belsey, 2002). Derrida demonstrated that de Saussure 'denounces writing as variously monstrous, sinful, unnatural, perverse, tyrannical, pathological' (ibid: 77). Belsey (ibid) asks what it is that is so important that is threatened by the existence of writing. According to Derrida, writing continues to signify in the absence of the writer and, as a result, sense can be made of writing long after the writer has left the scene:

> Writing, therefore, demonstrates that sense may always be something we make, that there may be no single true meaning, guaranteed by the word of the author, the *cogito* of consciousness, present to itself in thought, and uttered (outered, expressed) in the immediacy of unfallen speech. In this way writing threatens the *logocentric* tradition of Western thought (ibid: 78, original italics).

For de Saussure, meaning resided purely in the sign, which he divided into two parts: '[O]n the one hand, the signifier, the sound or the visual appearance of the word, phrase or image in question; on the other, the signified, its meaning' (ibid: 11). Meaning is inscribed in language within particular cultural contexts, and there is no absolute reality or truth or meaning outside this, in terms of human social experience. Meaning varies from one cultural context to another and the human subject is both subject to meaning, which is learnt from birth and, at the same time, is the subject of their own life (ibid.). De Saussure's phonocentrism and logocentrism, which he inherited from centuries of Western culture, were contradicted in his own work by his belief that meaning, in the human social world, existed only within language itself, and that language did not refer to ideas or things in the world beyond itself. Prior to this, language had been understood as signs, representing meaning that existed somewhere else (ibid.).

Derrida's (1976) deconstruction of de Saussure's work, along with his deconstruction of a similar contradiction within the work of structuralist anthropologist, Claude Lévi-Strauss (1973), was fundamental in the development of post-structuralism (ibid.). In the process of these deconstructions, Derrida challenged traditional Western binary thinking, and the idea that one part of a binary is considered superior to the other, which can be traced back to the privileging of mind over body by René Descartes in 1637 (Cottingham, 1997). For Derrida, meaning resides in the effect of the trace of the more neglected or disparaged aspect of a binary, which can be found within the privileged aspect (Belsey, 2002). Belsey (ibid: 83) gives the example of the way we define nature:

> Not by reference to flowers and trees, probably, since they are found in parks and can be cultivated, but as wildness, the absence of culture. By reference, in other words, to the term that is excluded by and from nature itself. And yet it is precisely from within culture that we are able to identify nature at all. The one term cannot be excluded from the meaning of the other. Meaning depends on difference.

Meaning depends on difference and is, therefore, always deferred. Every signifier contains within it another signifier, and so on: '[T]he nature of the signifying process undermines [the] notion of structure… signification is itself a process of infinite play' (Callinicos, 2007: 277). Meaning, for the post-structuralists, cannot be nailed down and cannot be found outside language. Meaning, for human beings, is socially constructed within language.

Rasiński (2011: 8) notes the heterogeneous nature of the concept of 'discourse' within post-structuralist theories but cites Philips and Jørgensen (2002) who 'offer the general definition of discourse as "a particular way of talking about and understanding the world (or an aspect of the world)"'. Rasiński (ibid: 8) states that: 'In Derrida the idea of discourse serves as a model for the "deconstructionist" reading of texts whereby the notion of the "center" is marginalized'. For Foucault, however, Rasiński (ibid: 8) suggests that the key issue appears 'to lie in determining the status of what is called "the human sciences" as a form of knowledge whereby the question of the functioning of language intertwines with questions concerning its relations with the social and institutional environment that governs the production of statements in a given time and place'. Jones-Devitt and Smith (2007: 137) note the flexibility of the term 'text', beyond that which is written, and suggest that '[p]ieces of art, web pages, buildings, transcripts of interviews and music can all be regarded as textual'. Jones-Devitt and Smith (ibid: 137) cite Rolfe (2001): '"Thus, a text (what is written) also takes on extended form as a shorthand for all attempts at representation"', and they note the conception within health and social care practice of the body itself as a form of text, being the site of both matter and discourse (ibid.).

Key figures within the post-structuralist movement included Jacques Derrida (2001, 1976); Julia Kristeva (1991, 1984); Roland Barthes (1972); Michel Foucault (2004, 1986, 1985, 1978, 1977, 1973, 1970, 1965); Gilles Deleuze (2014) and Judith Butler (1997, 1993, 1990). Aspects of the work of Barthes and Foucault were initially informed by structuralist thinking, and all followed individual, and different, theoretical paths but all were interested in the formation of the subject through differing meanings in language, and the possibilities for changing these meanings through resistance or challenge to that which is taken-for-granted within a particular cultural tradition (Belsey, 2002). The post-war French context of much of this work locates it in its own particular social and historical period, at a time when the relationship between power and resistance was very much alive in people's minds, following the German occupation of France (ibid.). Thus, post-structuralism itself became a new cultural reading of the way power relations in human society operate, although not one that was taken-for-granted by everyone. Callinicos, (2007: 277) notes '…the problematic way in which the work of what in many ways are quite different thinkers – notably Derrida, Foucault, and the philosopher Gilles Deleuze – has been marketed especially in the United States under the labels "post-structuralism" and "postmodernism"'. Belsey, however, (2002: 52) offers a broad definition, suggesting that 'poststructuralism thinks in terms of grammatical categories and talks about subject-positions':

> As a free subject, I plan my life (within certain obvious constraints), affirm my values, choose my friends (if they'll have me), and give an account of myself: "I am... this or that". But I do so on condition that I invoke (*subject* myself to) the terms, meanings, categories that I and others recognize, the signifiers we have learned in the process of learning our native language (ibid: 52, original italics).

3.3 Post-structuralism and Roma health and well-being

Michel Foucault

Michel Foucault (1926-1984) is often thought of as a maverick (Angermuller, 2014), by critics and supporters alike. Nevertheless, Foucault's work can be read as part of a trajectory from structuralism, through phenomenology and existentialism, to post-structuralist ideas (Gutting, 2005). Foucault, who was a historian of ideas, analysed the ways in which culture permits us to give an account of ourselves. Familiar everyday categories call us to account and, in this way, keep us in line with the norms and expectations of culture, that are constructed by culture itself (ibid.). In this way, we are recruited to become 'accountable, responsible citizens, eager, indeed, to give an account of ourselves in terms we have learned from the signifying practices of those societies themselves' (ibid: 53). In terms of those who deviate from this requirement, Foucault notes a shift from direct punishment of criminals by the sovereign state to practices designed to reconstruct offenders as conforming citizens (Foucault, 1977). The goal, in the second instance, is for the (reformed) citizens to work *by themselves* in accordance with the values of their society (ibid., italics added). However, Belsey (2002) notes that, for Foucault, power cannot exist without the possibility of resistance, although a price may be paid for challenging the cultural norms and expectations of one's time.

Callinicos (2007: 278) states that '[Foucault's] influence was chiefly expressed through a series of texts which, though they formally belonged to the genre of intellectual history, in actuality represented a novel form of historical writing'. Foucault's methods - archeology and genealogy - were those of historical investigation, rather than methods of philosophical analysis, despite his possession of degrees in philosophy and employment as a professor in academic philosophy departments (Gutting, 2005). His archeological studies, written in the 1960s, (Foucault, 1973, 1970, 1965) sought to identify what Foucault called the 'episteme', or the underlying conceptual structure that constituted a specific historical epoch (Callinicos, 2007). In the 1970s, Foucault developed his genealogical method, through which he studied the prevailing apparatus, or 'dispositif', of the relationship between power and knowledge, such as discourses, institutions, laws, administrative measures or scientific statements (ibid.). The idea of a single 'episteme' gave way to a conceptualisation of multiple smaller factors contributing to wider discourses (ibid.).

Influenced by Nietzsche (1844-1900), and his conception of the 'will to power', or of the movement of power from one site of combat to another, Foucault took up the idea of humanity moving from one system of domination to another (Callinicos, 2007). For Foucault, power could be productive, as well as constraining or repressive. He thought that power could produce knowledge, and that knowledge could, itself, transform power (ibid.). Throughout Foucault's work, the question of how the subject is constituted in relation to discursive practices or to power is always present but is never finally answered. Although Foucault 'emphasized the importance of avant-garde literature's decentring of the author and the psychological subject' (Gutting, 2005: 62), he moved beyond the idea of the autonomy of language (Callinicos, 2007). Gutting (2005: 9) suggests that there is 'a fundamental tension in Foucault's life and thought between aesthetic contemplation and political activism', and it is as if Foucault constantly seeks to free the individual from the tautologies of his own work, in order that she or he might be able to resist the mechanisms of control that he uncovers.

Huub van Baar

One of Foucault’s key theoretical ideas was that of governmentality, which offers a way of conceptualising modern forms of government (Foucault, 2004). In his study of the European Roma, van Baar (2011a: 6) states: ‘My central methodological approach is to understand knowledge, expertise, and tools of development, improvement, and empowerment as specific dimensions of intersecting and overlapping forms of government’. Van Baar (ibid: 28) notes that Foucault’s discussion of power in terms of governmentality has led to new perceptions of ‘the state, state-related practices, and the state’s sovereignty in an age in which forces commonly attributed to various processes of globalization have increasingly contested the state or at least resituated it in new networks of multiple governing agencies’. Van Baar (ibid.) examines the nature of resistance to these new forms of governance in relation to the Roma in present-day Europe. Discourses at play here include conceptions of minority ethnic status, citizenship and the ‘improvement’ of populations, aimed at their full integration and active participation, culturally and economically.

Van Baar (2011a) uses the notion of governmentality, (la gouvernementalité), drawn from Michel Foucault's studies of power, and described by Foucault (2004) as an assemblage of institutions, procedures and thought processes used to manage populations, as well as family groups and the individual's management of the self. In terms of the governing of populations, governmentality constitutes the totality of the exercise of power towards the achievement of economic goals, incorporating policing in its broadest sense, and encompassing subtler internalisations of self-control.

Van Baar (2011a: 6) states that, for Foucault:

> [G]overnment relates to the fields of possibilities and power relations instigated by the multiple intersections of self-government, the government of others, and the government of the body politic. From this viewpoint, notions such as the subject, the family, the community, and the state are understood as the effects, rather than the unproblematic starting points, of specific regimes of government. Here, government is in the first place understood as the ‘conduct of conduct’.

The concept of governmentality offers a multi-dimensional lens through which to view processes of governing in all its forms including, van Baar suggests, forms of resistance. He notes (ibid: 15) that, ‘Though particular governmentalities and counter-conducts can be analytically distinguished, in practice they appear in conjunction with each other’, echoing Foucault’s observation that they are inseparable from one another.

Alongside the concept of governmentality, and echoing Elias (1939 [Callinicos, 2007]), Foucault developed the notion of bio-power, which he suggested emerged during the eighteenth century together with the category of human nature (van Baar, 2011a). Foucault stressed the use of bio-power in regulating populations: 'Bio-power is conceived as a form of power that intensively regulates life and its mechanisms, and that governs and manipulates bodies, whether on an individual or a collective scale' (ibid: 29). Bio-power operates in two dimensions; the anatamo-political, or disciplinary, element working at the level of individualised bodies, and the bio-political, or regulatory, level, working at the level of the collectivised body of a population (ibid.). Van Baar (ibid: 29) states that, 'Bio-political regulation includes the management of processes of collective life through governing the health, happiness, wealth, security, longevity, productive capacity, or the reproduction of populations'.

Van Baar (ibid.) notes several shifts in Foucault's thinking, from his initial proposal of a move from sovereign governance to disciplinary forms of governance (Foucault, 1977), which implied a clear replacement of one by the other. This was followed by a conception whereby sovereign governance remained, with both modalities of power working alongside each other, differently but complementarily. A further series of conceptual shifts led to the idea of a multiplicity of technologies of power –sovereignty, discipline and security – working differently, at different times, in different places (van Baar, 2011a). Van Baar (ibid: 33) states that: 'The focus on non-totalizing forms of assembling heterogeneous and disparate elements that characterizes the shift toward governmentality has also consequences for theorizing agency, freedom and resistance'. The move to an analytics of government, or governmentality, opened up in Foucault's work the space for a less repressed and controlled subject. Van Baar (ibid: 33) cites Collier (2009), suggesting that '[Foucault's] post-1976 work "places particular emphasis on the work of actors – *thinkers* – who constitute existing ways of thinking and acting as problems, and seek to reform and remediate them"' (original italics). The Roma, caught in van Baar's own (2018) conception of the nexus between development and security, nevertheless have some possibility of initiating change.

Three aspects of van Baar's (2011a) work were, thus, particularly relevant to the present study's focus on Roma health and well-being experiences in London. Firstly, van Baar's use of Foucault's concept of governmentality allows current constructions of the Roma in Europe to be understood, and effects of the contradictions within these constructions to be considered. Secondly, van Baar considers Foucault's notion of bio-power in the context of modern techniques of governmentality, and this suggests questions regarding the governance of Roma people across Europe, in relation to their health and well-being. Finally, van Baar is interested in the possibilities for resistance, on the part of the Roma, to aspects of governmentality and bio-power affecting all aspects of their lives, thereby offering a theoretical route towards considering the agency of Roma people in the area of health and well-being.

The governance of Roma health and well-being

The majority of interventions directed at improving the circumstances of Roma community members, whether at European, member state or NGO level, focus on four main aspects of life: education, employment, health and housing. Van Baar (ibid: 7) notes that, for Foucault, ‘In order to contribute to the well-being of a population, government is conceived as the endeavor to shape, regulate and direct human conduct by “more or less considered and calculated modes of action” (Foucault 2000e: 341)’. Foucault has seen modern European government of populations as being, ‘aimed at improving their *well-being*, that is, their *welfare*, *health*, *fertility*, wealth, productivity, security, *longevity*, *happiness*, and the like’ (ibid: 7, italics added). Van Baar (ibid: 7) notes that: ‘The will to improve the condition of European populations has become a crucial element of historically diverse European arts of government and is key to both the idea of Europe and contemporary modes of European minority governance’.

The EU has health as one of its target areas of improvement for Roma people, but the EU also sees the Roma as a threat to the smooth governance of its territories (van Baar, 2018); the Roma must be brought into line with other citizens of member states, so they can play their part economically and, to do this, they must be in good health. However, van Baar (ibid.) argues that bio- and geopolitical conditions in Europe have led to a merging of development and security goals, resulting in a situation in which programmes aimed at improving the living conditions and life chances of the Roma are endangered, and where poverty in Europe has become racialised (ibid.).

Viewed through the theoretical lens of Foucault’s concepts of governmentality and bio-power, the project to improve the health and well-being of Roma people in the UK, which, until recently, has been part of the European project, is subject to a further contradiction. McDonnell et al. (2009) note the transition within the NHS in the UK from welfarism to neo-liberalism, and the concomitant discourse in which the individual becomes responsible for managing her or his own health and well-being towards the policy goals of the NHS and of national government. Interventions, including those initiated by European institutions, arise within a neo-liberal discourse and the present researcher was interested in how these interventions are interpreted and acted on within the NHS, within the UK voluntary sector, and by Roma people themselves, as the NHS transforms from a pillar of the welfare state to an economy driven arm of neo-liberal government (ibid.).

So, how does this impact on the Roma, who are constructed as 'victims', as well as irresponsible and 'undeserving' (The Guardian Editorial, 2012; BBC News Magazine, 2010)? How does this play out in terms of improvements or changes to their health and well-being? It is argued in the present study that the Roma, and the interventions regarding their health and well-being, are caught in this contradictory place, and that this may be a contributing factor to the reported slow progress in this area (Jovanovic, 2015). For example, the question of responsibility appeared to be central here, represented by the neo-liberal move towards individual responsibility for health and healthcare. McDonnell et al. (ibid: 102) point out that ‘in the shift from welfarism to neo-liberalism, governmentality studies stress how practices of governing increasingly emphasize the ideal of the active subject’. Who is responsible, then, for 'improving' Roma health and well-being? Is it the EU, or individual nation states, or healthcare professionals, or is it the Roma themselves? Mc Donnell et al. (ibid.) suggest that this approach, following the World Health Organisation’s agenda targeting diseases associated with lifestyle, has impacted on all service users in the past two decades.

Foucault’s notion of governmentality offered a way of understanding the ‘mode of subjectivity that is fashioned out of the techniques and practices associated with the governance of health and a “neo-liberal governmental rationality”’ (ibid: 102). The subject was to be self-managing and self-regulating and should follow a lifestyle that would avoid risks associated with ill-health and disease (ibid.). Nikolas Rose (1999: vii), in his ‘…contribution to the genealogy of subjectivity’, discusses the significance of what he calls the ‘psy’, or psychological, sciences, in enabling the governance of human beings ‘…in ways that are compatible with the principles of liberalism and democracy’. Rose (ibid: viii) suggests that: ‘These new forms of regulation do not crush subjectivity. They actually fabricate subjects – human men, women and children – capable of bearing the burdens of liberty.’

McDonnell et al. (2009: 92) note that ‘Foucault accords a special status to medicine both as a dominant discourse in generating ideas about the body, health and disease and, at a much deeper level, rendering control over the vitality of the body, of life itself and the formation of self (subjectivity) as political objects of government’. Foucault’s concepts of governmentality and bio-power offered a theoretical landscape with which to approach the present research into the health and well-being experiences of Roma people in London. Within this landscape, concepts relating directly to representations of the Roma, to their marginalisation, and to their own agency, were developed and problematised from a post-structuralist perspective, in order to generate ‘analytic tools’ for use in the discussion of the findings.

To the present researcher’s knowledge, a post-structuralist discussion has not previously been used in a study on Roma health and well-being in the UK. Following Derrida and Foucault, post-structuralist thinking has been developed by many theorists and now offers additional conceptual tools that can be applied to empirical research. David Howarth (2013) examines what he calls three generations of post-structuralist thinkers, whose work built on that of the structuralists, de Saussure and Lévi-Strauss. After looking in detail at the first generation of post-structuralists, including Derrida, Foucault, Kristeva and Deleuze, and the linguistic turn, Howarth moves on to consider the second generation.

Amongst works by second generation post-structuralist thinkers, Howarth highlights those of Edward Said (1995); William Connolly (1991); Judith Butler (1990); and Ernesto Laclau and Chantal Mouffe (1985). Howarth (2013) notes that this second generation of post-structuralist thinkers, working from the late 1970s onwards, utilised the conceptual resources of the original post-structuralists to rework basic concepts and problems in cultural theory. Key concepts in the social sciences, including power, class, identity, ideology, representation and subjectivity, alongside structure and agency, gender, and the nation state in a globalised world were reconsidered by these theorists. Howarth (ibid.) then notes that a third, and growing, generation of researchers has continued to develop post-structuralist thinking within social and political theory, so that post-structuralism’s originally highly theoretical ideas might offer a more practical application within empirical research.

Howarth (ibid.) examines this history of post-structuralist thinking in great detail, before advancing his own propositions regarding the use of post-structuralist concepts within present-day social and political analysis. Within the broader background of Foucault’s concepts of governmentality and bio-power in relation to Roma health and well-being, post-structuralist understandings of voice, culture, identity, agency and nomadism informed the discussion of the findings gathered through the empirical aspect of the present study. These concepts are examined in section 3.5.

3.4 Post-structuralist ontology and epistemology in social research

3.4.1 Post-structuralism and ontology

Locating epistemological positions within beliefs about the nature of reality makes sense from a traditional Western philosophical point of view. Conventionally, ontology is discussed first, with epistemological beliefs following from an ontological position. Post-structuralism, though, poses a fundamental challenge to Western metaphysics, which requires a different way of thinking about the relationship between ontology and epistemology within a post-structuralist paradigm. Post-structuralist thinking views meaning, for human beings in their social world, as a closed system, whereby meanings are created within language through the play of an endless chain of signifiers (Belsey, 2002). For most post-structuralist thinkers, meaning can only be communicated through textual discourse and has no existence that can be experienced beyond the symbolic order. Callinicos (2007) suggests that the most significant new idea in social theory since the 1960s has perhaps been a focus on the importance of language. No longer taken for granted, language became the object of much philosophical study. Discussing the work of de Saussure, Callinicos (ibid: 269) states, 'Saussure argues that "the linguistic sign unites, not a thing and a name, but a concept and a sound image"'. For de Saussure, it is the differences within language that are important. These differences exist only within the linguistic system itself and have no reference to anything outside it:

> Saussure's holistic theory of meaning thus brackets the question of the natural and social context in which utterances are made, and that of reference, that is, of their relationship to the items in the world to which they refer. Saussure himself never denied the importance of context and reference, but by focusing on the internal relationship between signifiers and signified he made it possible to conceive of language as an autonomous system (ibid: 269).

Belsey (2002: 9) notes the differences between languages in naming the same things, or in the use of gender and tenses:

> We are compelled to conclude either that some languages misrepresent the way things are, while our own describes the world accurately, or that language, which seems to name

> units given in nature, does not in practice depend on reference to things, or even to our idea of things.

Post-structuralism is thus not concerned with ontology in the traditional Western philosophical sense as, from a post-structuralist perspective, the nature of being or of reality can only be conceived of through culturally specific discourses (Gutting, 2005). Post-structuralism theorises ontological understandings as contingent upon certain historical moments and it cannot logically accommodate an absolute reality beyond human cultural meanings. Belsey (2002: 71) notes:

> The issue here is not what exists, but what we can accurately *say* exists. Faithful to Saussure, poststructuralism is concerned with what goes on in language. Truths (or otherwise) are told in language. Poststructuralists don't (normally) doubt that there is a world: their anxiety concerns what we can claim to know about it with any certainty (original italics).

In conceiving of meaning and the transmission of meaning in this way, post-structuralist thinkers posed profound questions regarding the Western metaphysical tradition from Plato onwards. Belsey (ibid: 74) states that Derrida's '*Of Grammatology* delivered a resounding challenge to the entire tradition of Western philosophy, and although the book has been endlessly misread, misquoted, and denounced, its arguments have not so far been effectively refuted'. Callinicos (2007: 277) notes that the idea of structure is undermined by the unending nature of the signifying process, and that '[t]he only way in which this movement could be halted would be if one could posit a "transcendental signified" outside language which is immediately "present", that is, to which we somehow have direct access without the mediation of language'. However, for Derrida, this would be to believe in 'the metaphysics of presence', which he saw as a philosophical error. Within the process of signification, an original or transcendental signified 'is never absolutely present outside a system of differences' (ibid: 277).

In post-structuralist thinking, the question to be asked of philosophy is not one regarding the limits of what human beings might be able to understand or to know, or what is knowable and what transcends this. It is, rather, a question regarding differences between philosophical projects at different historical moments (Gutting, 2005). For Foucault, philosophy is not a search for absolute truths, which exist beyond history. A particular philosophical project is, instead, historically contingent and Foucault used his archeological method to unearth the underlying 'contingencies masked as necessities' (ibid: 60). Foucault examines Immanuel Kant's (2009 [1784]) critique of the Enlightenment, from which time onwards human beings began to use their own reasoning rather than relying on traditional doctrines: ‘Kant, for example, argued in his first Critique that theoretical reason could not be legitimately applied to “limit-questions” such as the origin of the universe or the immortality of the soul’ (Gutting, 2005: 57). What interests Foucault, however, is not what the limits of reason might be but the fact that Kant has asked new questions of philosophy: ‘Accordingly, just as Kant… asks how his situation is different from that of his predecessors, so Foucault asks how his situation is different from Kant’s’ (ibid: 58).

Gutting (ibid.) notes that modern (Western) philosophy from Descartes onwards has been focused on whether the representations that human beings make of the world actually match the world as it is beyond the human mind. Kant took this questioning further, to ask how it is that human beings can represent anything at all. Kant believed that, for an object to be experienced and represented, the object must exist in space and time and within a network of causal laws (ibid.) In Kant’s view, we can only know the world as we experience it, the phenomenal world, and we cannot know the world as it is in itself, or the noumenal world. For Kant, human beings, in their use of reason, operated in a transcendental domain, determining what may or may not be possible to know in the world of empirical experience. At the same time, human beings could be objects of study in the empirical domain (ibid.). Foucault, however, questioned this, asking how ‘a single unified being can be simultaneously the transcendental source of the possibility of knowledge and just another object of knowledge’ (ibid: 65).

The practical application of post-structuralist ontology

David Howarth (2013) seeks to examine the concepts of social and political theory from a post-structuralist perspective, in order to develop the practical application of post-structuralist thinking to research in the social sciences. Drawing on four out of five possible theoretical paths that he identifies, leading, ‘from the concern with language and ontology to social theory’ (ibid: 102), Howarth locates his work within wider, ‘efforts to develop poststructuralist theory into a living tradition of social and political research’ (ibid: 16).

Howarth (ibid: 91) notes that, not only do many post-structuralists agree with the importance of ontology within social and political theory, but that:

> [I]t is the commitment of various thinkers to a common core of ontological presuppositions that defines poststructuralism as a distinctive style of social theorizing. This means that questions of knowledge, method, and research design require the articulation and clarification of one’s ontological assumptions, and that social research

> and its substantive outcomes depend upon a prior set of ontological choices.

In philosophy, the concept of ontology has been taken to be a concern with the nature of existence, or what exists. In the social sciences, ontology refers to the nature of social existence (ibid.). Howarth (ibid: 93) suggests that post-structuralists subscribe to what he calls, ‘a minimal form of realism – the existence of things external to human consciousness’, but they do not attribute properties and causal mechanisms to objects outside human language and discourse. Post-structuralists are not idealists – they do not deny the existence of a reality that is independent of thought. Human beings can only conceptualise objects and things that they encounter through language and discourse, but these meanings are not exhaustive. The symbolic order can always be disrupted by ‘the Real’ – Jacques Lacan’s (1993) term for that which cannot be symbolically represented (ibid.). Meaning and function are contingent and can change according to historical context and circumstance. This means neither that do they not exist, nor that they can be spoken about with absolute certainty. Post-structuralism lies somewhere between idealism and traditional realism.

In considering the nature of a post-structuralist ontology, Howarth (ibid.) starts with the work of Martin Heidegger (1962). Heidegger differentiates between differing modes of being, including Being itself (ibid.). Howarth (2013: 98), referring to Mulhall (2001), notes: ‘In other words, ontological inquiry must not only investigate the conditions of any particular ontical science to clarify its basic concepts, but it must also investigate the conditions of possibility of the ontological conditions themselves’. Heidegger believes that, for human beings, or Dasein (‘being-there’) (ibid: 96), the nature of Being itself and its way of being are inextricably linked. For Heidegger, ‘human beings are composed of an infinite set of contingent possibilities… and are not only endowed with the capacity to choose their projects but are also able to transform their identities in the process of choosing’ (ibid: 99). Heidegger historicises the ontological difference between Being and beings (ibid.). Howarth (ibid: 100) notes that, ‘[h]ere the different epochs of Being become the frames or spaces which make things intelligible’. For Heidegger, the understanding of Being in the modern age turns around the notion of representation. It is the representation by human beings of whatever is that determines a particular understanding of Being. Howarth (ibid.) notes that Heidegger’s investigation of differing Western orders of knowledge parallels Foucault’s (1970) notion of an episteme.

Howarth (ibid: 101) refers to Heidegger's writings, to endorse the belief that a study of ontology is necessary for social and political theory and practice: 'Any study of beings, including human beings, presupposes an investigation of Being, and any investigation of human beings is simultaneously an investigation of the investigator, that is, a situated human being, who investigates'. Howarth suggests that both structuralists and post-structuralists endeavour to uncover underlying rules and logics of the meanings and practices that are encountered at the surface level of the social world (ibid.). Whilst structuralists privilege binary oppositions, post-structuralists, such as Laclau and Mouffe (1985), are interested in, 'the logics of equivalence and difference' (ibid: 113), to explain the way in which social relations are politically structured. In this way, social antagonisms are explained by means of the construction of an Other, experienced as blocking the identity of a self (ibid.). Howarth (ibid: 126) suggests that post-structuralists and post-Marxists have emphasised the 'the relational and incomplete character of social formations, whilst also stressing the primacy of politics in their constitution'.

With regard to traditional approaches to the relationship between the nature of social structures and the ways in which those structures facilitate or inhibit political agency, Howarth (ibid: 151) suggests that this cannot be understood through a definitive theoretical resolution. For Howarth (ibid: 182), 'the dilemma of structure and agency is a rift in the very fabric of the human condition: this rift can both unsettle structures and practices, whilst making possible novel interventions and practices'. He seeks to offer a critical explanation of social phenomena at particular historical moments, through unpicking traditional binary oppositions and incorporating affect, emotion and the unconscious into his account of these phenomena. Howarth (ibid.) suggests that affects and passions contribute to moments of agency, and also play a part in the persistence of certain social structures.

Human beings are born into, and are always immersed in, a system of meaningful practices (ibid.), which shape their identities. However, at moments of crisis, the opportunity arises for new identifications to be made, with newly available ideologies, discourses or beliefs, or, as Laclau (1990) suggests, for new mythical ideas to lead to the creation of new 'collective social imaginaries' (ibid: 164). Howarth (ibid.) notes Laclau's differentiation between subject positions and political subjectivity, the former being any available positions with which an individual can identify themselves within existing social orders. Political subjectivity, on the other hand, refers to newly adopted identities, which only become available to an individual or a collective at the moment of social crisis or dislocation. Just as post-structuralism sees the components of language, texts and discourses as always contingent and containing the trace of different possibilities, so Howarth (2013) and Laclau (1990) see social structures and individual and collective identities as unstable and constantly at risk of disruption. In the ways described, the challenge of post-structuralist thinking to Descartes' privileging of human consciousness, and Kant's humanist positioning of the subject as 'the source of the necessary conditions for the possibility of any knowledge of the world' (ibid: 65), offers a different view of the way in which subjectivity is constituted and a different relationship with epistemology.

3.4.2 Post-structuralist epistemology

Post-structuralism in the English-speaking world has largely been received as a form of linguistic idealism, with a focus on the deconstruction of texts (Callinicos, 2007). Belsey (2002: 87) states:

> Saussure's diagrams of the sign as a self-contained oval, with a line across the middle dividing signifier from signified, might give the impression that each signifier brings with it its own inseparable, single meaning. Deconstruction undoes that impression, pushes meaning towards undecidability, and in the process democratizes language. Binary oppositions do not hold, but can always be undone. The trace of otherness in the selfsame lays all oppositions open to deconstruction, leaving no pure or absolute concepts that can be taken as foundational. Meanings… are not individual, personal or subjective, since they emanate from language. But they are not given in nature or guaranteed by any existing authority either.

Following Derrida (2001, 1976), deconstruction, as a method of interrogating discourse, has been used by Foucault (1973, 1970, 1965); Barthes (1972); and others (ibid.). Nevertheless, Callinicos (2007: 277) points to the problematic way in which the work of very different thinkers has been grouped together under the labels 'post-structuralism' and 'postmodernism': 'The significance of post-structuralism is less that Derrida or Foucault wish to deny that tables and chairs exist when we are not talking about them than that the subversion of the Saussurian model of language created a space within which certain themes deriving from Nietzsche could be pursued.'

The move away from structuralism, particularly from structural thinking about history, meant that chance and contingency assumed greater significance. If the world is constituted by discourse, all ideologies, including that of scientific rationality, could be viewed as forms of domination. This conception fitted the disillusionment with Marxism of Foucault and many of his contemporaries, following the ambivalent outcomes of the French uprising of May 1968 and crimes committed by a succession of Stalinist regimes (ibid.).

Whilst agreeing with the importance of critique proposed by the Enlightenment, Foucault reversed Kant's question regarding the limits of knowledge. Instead of asking what the limits of human knowledge might be, he asked what was singular and contingent within that which was presented as universal: 'Foucault, like Nietzsche… rejects the ideal of philosophy as a body of autonomous truths' (Gutting, 2005: 60). However, Foucault's archaeological method enabled him to move beyond examining discourses simply as groups of signifiers carrying meaning or representation (Callinicos, 2007). He was now interested in 'discursive practices', or the articulation of particular discourses and the institutional contexts that gave them their identity: 'Thus, even at this stage, Foucault was moving beyond the idea of the autonomy of language' (ibid: 279).

Callinicos (ibid.: 279) notes that, for Foucault (1977), knowledge is inseparable from power: 'There is no power-relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power-relations'. Foucault's contention was that, rather than there being a single 'episteme' or underlying conceptual structure pertaining to a specific historical time, a wide and heterogeneous range of means of power-knowledge existed, including discourses, laws and institutions: 'Power consists of a multiplicity of specific, localized relationships which together constitute the social body' (ibid: 280). For Foucault, power also generated 'points of resistance' necessary to the functioning of these relations (ibid: 280). In this model, the individual continues to be de-centred and is the effect of power-knowledge, rather than the source of it. Through its effect on bodies – individual and collective – power-knowledge enacts itself (ibid.).

Foucault's critique of the Enlightenment, modernity and the hegemony of reason offered a challenge to the claim of objectivity of modern scientific rationality (ibid.). The theoretical physicist and philosopher of science, Bernard d'Espagnat (2006), working within a Kantian framework, suggests that philosophers are drawn more to the importance of empirical reality, whilst scientists tend towards the view that the purpose of science is to uncover the 'true' nature of mind-independent reality. D'Espagnat's interest is in the impact of quantum physics on the theory of knowledge. He suggests the crucial importance of assessing the implications of developments in contemporary physics for philosophical debates about realism versus idealism, and their implicit challenge to popular belief in 'a materialist-atomistic world-view' (ibid: 267). D'Espagnat notes the success of a general belief in this worldview:

> [t]o the extent indeed that within well-developed societies it has now become the instinctive, received "ontology" … We know that an atomistic materialism reducing the whole world to a set of atoms, particles and so on, interacting through distance-decreasing forces, is an experimentally disproved conception. However great the attraction is that it may exert on some minds, such materialism is just simply false (ibid: 268).

Within this critique, d'Espagnat clearly describes this worldview as a received discourse, which has the potential to be changed. The experimental findings of contemporary physics profoundly challenge the philosophical split between 'ontological reality' or mind-independent reality, and 'empirical reality' or the phenomena or totality of human experience (ibid.). However, the influence of the discourses of the Enlightenment, scientific rationality and transcendental idealism, for more than three centuries, is difficult to leave behind. D'Espagnat, himself, having noted the unity of the world and beings within it, described by quantum physics, retains the notion of the 'transcendental' through his positing of the idea of a 'veiled reality' existing beyond the combined phenomenal and noumenal worlds (ibid.). Viewed from the present moment in Western history, it is impossible to know if our attachment to the transcendent is simply the product of being immured in a philosophical discourse, reflects a yearning for 'organic being outside signification' (Belsey, 2002: 58) or is indicative of an instinctive sense of the source of Being. As Belsey (ibid: 62) states: 'Perhaps in the end the most compelling passion, the one that is never satisfied, is the desire for knowledge, the longing to push back the limits imposed by the symbolic order'.

Recourse to dictionary definitions, likewise, shows the prevailing discourses as the sources of those definitions. The Oxford Living Dictionaries (2018) define 'ontology' as, 'The branch of metaphysics dealing with the nature of being', and 'ontic' as, 'Relating to entities and the facts about them; relating to real as opposed to phenomenal existence'. The French Dictionnaire Larousse (2016) defines 'ontologie' as, 'Science de l'être en soi' or 'The science of being in itself', echoing Kant's description of the existence of an object as is it, independent of observation, as the 'Ding an sich' or the 'thing-in-itself' (Philosophy Pages website, 2018).

In addition, Justin Cruikshank (2011: 15) believes that positivism, that which can be scientifically verified, 'has ended up being unable to account for the positive development and application of knowledge because by making the authority of the senses the source of knowledge it ended up in idealism'. Notwithstanding its rigour, the scientific method, as it is used in everyday practice, is seen as relying on the senses of the observer to draw its conclusions and the idea of the senses as the source of knowledge is not questioned.

Despite this critique of the scientific method, Cruickshank, in his generalised critique of social constructionism (2011), suggests that a consistent approach to discourse as contingent renders research unusable, as a privileged truth claim cannot be made for its outcomes. Cruickshank's interest is in the development and application of knowledge through research, and he cites Sayer (2005), who argues that social constructionists take up unacknowledged ethical positions to advance social or political change (ibid.). For Cruickshank (ibid.), social constructionism deconstructs but does not offer alternative ways of acting. However, his own position seems to be reliant on the ubiquitous discourse of ever-improving scientific knowledge, discovered by individuals, which is, itself, historically and culturally contingent.

McDonnell et al. (2009: 109), though, cite Delanty (1999), who suggests that '[by] revealing the contingent bases of knowledge, the relationship between knowledge and power appears less absolute and open to change'. In addition, Howarth's work (2013: 20) aims not only to 'address questions of high theory, but it also endeavours to explore the methodological and epistemological difficulties that arise in applying theory to empirical cases and problems'.

Howarth (2013: 13) stresses the diversity of views within the post-structuralist theoretical movement:

> My foregoing characterization suggests that poststructuralism is a homogenous tradition without differences and contestation. But this is a mistaken picture, for while poststructuralists are unified in their opposition to essentialism, scientism, and certain forms of naturalism, their approach is best conceived as a loose "style of theorizing" comprising different tendencies and inflections that have infiltrated and transfigured adjacent approaches and perspectives.

Tensions exist amongst post-structuralist thinkers dividing 'those who subscribe to a philosophy of immanence, and those who retain some conception of transcendence in their approach' (ibid: 19). Other areas of disagreement concern identity, power and political subjectivity, particularly conceptions of subjectivity and agency, as well as accounts of social structures and the state (ibid.). Questions of resistance and subjectivity occupied Foucault in his later work. Callinicos (2007: 282) describes Foucault's struggle with the contradiction between the critical position he takes up in relation to the history of domination, and the lack of a vantage-point for his position within a theoretical framework where every discourse is contingent and linked to power: 'What will to power do his genealogical histories articulate?'

Foucault links sites of resistance with local knowledge but the process of resistance is unclear, as 'Foucault claims that power constitutes the individuals through which it then operates. There is, moreover, no escape from it… It seems hard to see how the subjects of power can resist it – except when it wants them to' (ibid: 283). Foucault's way out of this closed system lay in his exploration of the history of classical antiquity and the development of his concept of 'technologies of the self' (ibid.). In this, Foucault described examples of self-improvement, where he saw the subjects as active in the process of administering power over themselves (ibid.).

In his final book, 'The Care of the Self', the third volume of his history of sexuality, Foucault treats philosophy itself as a way of life (Gutting, 2005). Gutting sees Foucault as suggesting 'two alternatives: truth as the product of individual self-creation on analogy with art; and truth-telling as a social virtue'. For Foucault, the search for truth as a way of living offered a space for ethics to return to his work; for it to live politically, as well as aesthetically (ibid.). It remains difficult to see, though, how living a philosophical life in search of 'truth' differs from following any other discourse.

It may well be the case, however, that human beings operate far more collectively than we in the West care to believe, with our attachment to the idea of rational individuality and freedom that Enlightenment thinking has offered us for so long. Belsey (2002: 73) seems relaxed with this, and notes that:

> Views are learned from somewhere, even if we cannot remember where or when, and *even if we are the very first person to bring together separate views to make a new one*. At the same time, there is no purely objective knowledge, because knowledge is necessarily the property of a subject. A fact may exist for ever, even if the human race dies out, but knowledge of it doesn't go on without a subject there to do the knowing (italics added).

This is also the position taken within the present study. Processes of resistance and change may well take place far more collectively than our lingering attachment to individualism demands. Certainly, the importance of the views of the collective on the actions of Roma people is one discourse examined within the analysis of the fieldwork of the present study. Narratives about the Roma leading to, and influencing, the very existence of the present study were also examined. Increased understandings of the ways in which different discourses operate and interact, in relation to Roma people's health and well-being, can in themselves contribute to change. The present study aimed to examine these discourses without pre-judging the outcomes.

Change occurs within human societies; things we once believed, nowadays, seem strange or even ridiculous; other things, unimaginable now, may one day seem quite normal. The role of the individual subject in the process of social change may be much more limited than we currently believe, but our attachment to this is probably the result of a historically contingent discourse. Not only does it probably not matter if the role of the individual in the process of social change is less significant than we currently think, but it could also be something of a relief from the pressures of the cult of individualism pervading modern capitalism.

In a historical period when virtual reality and artificial intelligence are being developed to a degree and at a speed that would have been unthinkable even a hundred years ago, the possibility of new and currently unimaginable culturally contingent discourses seems completely plausible. Gutting (2005: 66) suggests that Foucault's (1970) archaeological treatment of the main developments of 20th-century philosophy 'shows nothing more than that our thought is no longer guided by the modern episteme, with the result that we are, like readers of Borges' Chinese encyclopedia, faced with the stark impossibility of thinking *that*' (original italics). Foucault himself (ibid.), refers to Borges' (1942) fictitious taxonomy of animals as both humourous and as shaking up the familiar landmarks of our thought. Animals are divided into the following categories: those that belong to the emperor; embalmed ones; those that are trained; suckling pigs; mermaids; fabulous ones; stray dogs; those that are included in this classification; those that tremble as if they were mad; innumerable ones; those drawn with a very fine camel's-hair brush; etcetera; those that have just broken the flower vase; those that, at a distance, resemble flies!

Knowledge from a post-structuralist perspective in the research context

Howarth (2013: 267) states: 'in characterizing the poststructuralist tradition, I have argued that its proponents accept a common set of ontological, epistemological, and methodological assumptions and postulates'. He suggests that post-structuralist thinking is, 'a *practice* of reading, interpreting, criticizing and evaluating' (original italics).

The present study took up a post-structuralist epistemological position, seeing meaning as contingent, culturally determined and transmitted within language, through discourse and different types of text. The knowledge generated within the study, therefore, cannot be viewed as 'true' beyond the truths it holds within its specific cultural context. A wide range of discourses within the literature relating to the health and well-being of Roma people in the UK were examined, as well as those considered in the introduction, which looked at the historical and contemporary background to the lives of Roma people in Europe (van Baar, 2018, 2011a; Fraser, 1995). It was the impact of these discourses on Roma people's health and well-being in London that the present study sought to examine.

The findings and understandings produced within the present study were seen as culturally and historically contingent and required a high degree of reflexivity on the part of the researcher (Howarth, 2013). Reflexivity and ethical awareness belong together in Foucault's account of the centrality of ethics in the final analysis of his archeological and genealogical explorations of aspects of the social world (Gutting, 2005). Nevertheless, ethical positions are understood as reflecting the values of culturally contingent discourses.

3.5 Analytic concepts

In order to focus the extensive scope of post-structuralist thinking on the specifics of the present study, the concepts of voice, culture, identity, agency and nomadism are used to problematise the findings from the fieldwork, in relation to the literature. Each of these concepts has direct relevance to narratives about, and representations of and by, Roma people, impacting on their health and well-being across Europe and in the UK.

Within the present study, each concept is, itself, problematised using the core ideas offered by post-structuralism, in contrast to their more traditional definitions. Post-structuralist thinking understands language as the carrier of meaning within the context of human society (Callinicos, 2007; Belsey, 2002). In this reading, concepts are situated in socially, culturally and historically contingent contexts. Each of the concepts selected for use in the theoretical framework of the present study is, therefore, understood according to particular societal and historical moments. Post-structuralism arose in response to a structuralist paradigm, in which concepts were seen to represent fixed and foundational meanings (Lévi-Strauss, 1973). In contrast to this, post-structuralism sees meaning as constructed within language, and as fluid and constantly shifting, according to cultural and historical processes of change (Belsey, 2002). The concepts of voice, culture, identity, agency and nomadism exist as parts of ever-changing chains of signifiers (Callinicos, 2007; Belsey, 2002). In addition to an understanding of the fluid nature of signifiers, post-structuralist thinking deconstructs supposed binary oppositions, to show that each aspect of a pair of seemingly opposite terms is contained in the other, and that neither can exist outside its definition against that which it is not (Derrida, 1976). The privileging of one aspect of a binary pair is, therefore, put into question by its dependence on the other aspect of the pair, which is often derided (ibid.). As a result, concepts that are problematised using post-structuralist ideas both challenge essentialising definitions and put into question the values that historically and culturally contingent moments place on specific terms. In addition, these concepts do not operate in isolation but interact with one another in complex ways that are considered in the present study in relation to Roma health and well-being.

In sections 3.5.1 to 3.5.4, the relevance to the present study of the concepts selected is outlined, together with an indication of key authors whose work is used to theorise them, in relation to post-structuralist thinking. Section 3.5.5 looks briefly at the concept of intersectionality, which is used to bring a more nuanced understanding to the findings from the individual interviews, reported in Chapter five.

3.5.1 Culture

The concept of culture has frequently been used to represent Roma people as a homogenous group, subject to marginalisation by others, and to a conception of Roma culture as restrictive and unchanging. In this discourse, Roma people become passive victims of static external structures, within and outside Roma groups. Supportive, as well as disparaging, narratives that represent Roma people in this way contribute to keeping them in a place from which they cannot move (van Baar, 2018). Post-structuralist thinking, however, problematises a static cultural tradition, seeing this as historically contingent and always subject to resistance and processes of change. Complex understandings of culture, and processes of cultural change, are informed in the present study by the work of Williams (2010), Belsey (2002), Rose (1999) and Hall (1996). The work of Bhabha (1996) and of Robins (1996) adds to an understanding of culture as moving flexibly between tradition and modernity.

In relation to marginalisation, it might be suggested that Roma cultural and symbolic boundaries between themselves and gadźé, or all non-Roma people (Fraser, 1995), constitute self-exclusion from the non-Roma world, on the part of the Roma themselves. However, Fraser (ibid.) notes the blurring of these boundaries in certain contexts, and the complexities surrounding notions of Roma ‘authenticity’ and identity. In their study of Romanichal Gypsies in the UK, Bhopal and Myers (2008) suggest that, while cultural boundaries may provide protection for members of Gypsy groups, power is always at play in processes of inclusion, exclusion and self-exclusion. Whilst dominant, hegemonic discourses may be more powerful than cultural discourses within Roma groups, ‘…the precise balance of power still seems more open to debate: the formation of boundaries is not therefore a one-way process, and it is certainly not one in which all control has been wrested from Gypsy communities' (ibid: 107). In this instance, Romani agency is demonstrated.

These observations reflect Foucault's (1978) interdependent relationship between power and resistance, as well as a post-structuralist understanding of an opposite always waiting in the wings, to overturn the privileging of one aspect of a binary pair (Derrida, 2001). And, from the perspective of Deleuze and Guattari (1987), self-exclusion from mainstream narratives could be seen as an apt parallel to their notion of the liberating potential of the nomadic. Identification, which always '…requires what is left outside, its constitutive outside, to consolidate the process' (Hall, 1996: 3), is constantly subject to destabilisation by that which is left out (ibid.). As a result, 'otherness' can sometimes seem threatening, whilst 'sameness' appears more comfortable.

Glyn Williams (2010) distinguishes between categories of modernity and tradition, in relation to the status of cultures and languages, and this distinction is mirrored by the post-colonial split between western notions of Western and Eastern culture (Said, 1995). A similar dynamic is considered by Kevin Robins (1996: 61), in his discussion of '…the possibilities of dynamism and openness in cultural identities, and consequently with what inhibits and resists such qualities, promoting in their place rigidity and closure.' Robins's interest is in the relationship between Turkey and Europe, but his fascinating discussion about this relationship offers important insight into the static and inhibiting position that Roma people and their culture currently occupy within Europe (van Baar, 2018).

Robins (1996: 66) describes the culture wars at the heart of Turkey's long-standing, but unsuccessful, attempt to join the European Union: 'There is the demand that the Turks should assimilate western values and standards, alongside the conviction that, however much they try to do so it will be impossible for them to succeed.' This statement strikingly resembles van Baar's (2018) locating of Roma people in relation to the EU's programme of Roma 'improvements'. Robins (1996: 66) notes that the significant effects of such judgements on 'other' cultures sit together with a disregard for, and insensibility towards, them: 'It also shows – more tragically still – how cultural arrogance can turn into cultural hatred. When it is declared that the other is marked by an insurmountable particularity, and consequently can never be assimilated (converted) into our culture, then we have the basis of racism'.

Robins (ibid.) discusses the way in which modernity is insistent on constant change and questioning of values and meaning, in contrast to its conceptualisation of tradition as static, unchanging and irrational. ‘Modern’ western culture is characterised, he suggests, by this insistence on continuous change, which becomes the mechanism for its maintenance of its own existence. The supposed dynamism of modern culture is juxtaposed with an idea of traditional cultures that cannot move forward. The position of Turkey in relation to the EU is mirrored by that of Roma people in relation to the EU and to Europe itself. Robins notes the demand placed on Turkey to abandon what is seen as its traditional culture, in order to accommodate to Western notions of modernity. He describes the cultural sacrifice demanded by Europe which is, however, never accepted. Yet, these essentialising conceptualisations damage and underestimate culture and cultural change on the part of the West, in relation to both western and non-western cultures.

Cultural exchange, says Robins, is a two-way process. Developmental arrangements cannot be simply imposed from outside, and Robins (ibid.) discusses in depth Turkish endeavours to engage with modernity, from a range of perspectives that differ from that of western Europe. He stresses the diverse and complex nature of the cultures of Turkish people, as well as the fantasy of achieving cultural universalism on the part of the West itself. As is the case with the Roma people, there is no one, homogenous and static, Turkish culture. Cultural sites within any nation or community are multiple, and the responses of culture to culture’s demands are many. Robins (ibid.) calls for cultural exchange as a way forward, and as a way towards solutions to the demands of the modern global world. He points to the challenges that such a process of reciprocity would bring: ‘Cultural relationships develop through history, through the accumulation of stories that we tell ourselves about the others; often reflecting fear or ignorance, these stories evolve into mythologies that obscure and deny the reality of the others’ (ibid: 80).

The importance of culture lies at the heart of the post-structuralist tradition (Belsey, 2002), and the meanings that culture carries include meanings about culture itself. The use of a post-structuralist concept of culture allows narratives about Roma culture to be more closely examined. The origins of the Roma people, their ethnicity, language and culture, have been disputed since their first arrival in Europe (Margalit and Matras, 2007; Hancock, 2002; Fraser, 1995). Van Baar (2011a), writing from a post-structuralist perspective, examines competing views that critique the development of dominant cultural constructions of Roma people since the eighteenth century. Meanings, constructed by others, about Roma culture are seen to be malleable, uncertain and historically contingent, according to their perceived value as a political resource or a governmental tool, or as the cause of damage inflicted upon Roma communities. The construction of Roma culture as traditional and unchanging, in relation to health and well-being, is one of many narratives about Roma people, serving multiple purposes. The 'ordinary', everyday cultural experiences (Williams, 1958) of Roma people become secondary to discourses about Roma culture created by those with greater social or political power, whose own cultural values are taken to be the standard.

Natalie Forster (2018), in her narrative analysis of stories told by Irish Travellers, English Romanichal Gypsies and health practitioners, discusses the debate within the literature about these groups between cultural or structural factors as primary causes of poor health. Forster notes that a focus on these discourses precludes the opening up of a space for questioning the ways in which the health of Gypsies and Travellers is talked about. Discourses that assume poor health among members of particular communities fail to take account of community members' own relationships with their health status, and place members of these communities in a stigmatised position as 'victims' (ibid.).

In terms of the post-structuralist subject, Belsey (2002: 67) states: 'We are born human beings, in that we are the offspring of two human parents; we become subjects as a result of cultural construction *and* what culture represses, namely, the lost but inextricable real' (original italics). Consciousness, in the post-structuralist tradition, is understood as 'an effect of signification' (ibid: 66) and Belsey suggests that 'children generally do their best to become what language tells them they are' (ibid: 50). This process of becoming what culture requires, however, is not at all straightforward. The concept of governmentality as one of multiple sites of power (Foucault, 2004) applies not only externally but also within cultural groups themselves, as well as within a single individual. Babatunde and Moreno-Leguizamon (2012: 1) describe the need for healthcare practitioners to recognise that:

> …cultural practices are not frozen activities that determine unequivocally the behaviour of an individual. Culture is reenacted by individuals daily and is responsible for the embedded ambiguity in the way they react. Immigrants are neither in the old familiar place nor fully tailored to the new place - including, among other things, their access to or demand for health services that are mainly biomedically oriented.

Barthes (1972) famously explored the creation of myth that occurs during processes of cultural meaning-making. A post-structuralist concept of culture can contribute towards a recognition, and deconstruction, of the myths that surround members of Roma communities, as well as seeking to determine whose interests are served by these mythic ideas. Writing about the work of Barthes, Belsey (2002: 31) states:

> Myth, Barthes explains, converts history into nature. And the task of the mythographer is to rediscover the element of history that motivates the myth, to elicit what is specific to a given time and place, asking what interests are served by the naturalization of particular conventions and values.

Barthes believed that, beyond the meanings conveyed within language by individual signifiers, stories told using language or visual signs within different cultures at different times conveyed the value systems of those specific cultural moments. Cultural narratives, or myths, could be deconstructed to show the cultural values underpinning a particular image or text (ibid.). In the case of the Roma, popular narratives include a belief that Roma people and Roma culture are ‘backward’ and belong to a tradition that is incompatible with modernity (van Baar, 2018). This binary notion both privileges the ‘modern’ above the ‘traditional’ and fails to recognise cultural exchange and movement between these two positions. Such a belief precludes the possibilities either of Roma people having knowledge that has current value and usefulness, such as knowledge about health, or of Roma culture as adaptable to change.

3.5.2 Nomadism

Also with regard to marginalisation, the concept of nomadism attracts negative value when applied to Romani and Traveller people (Monbiot, 2022, 2020; McVeigh, 1997). Roma people living in CEE countries were forced to settle during the 1960s (van Baar, 2011a). However, the present thesis argues that the negativity attaching to popular ideas about nomadism remains, in relation to Roma migration to Western Europe. In the present study, the philosophical concept of nomadism, developed by Deleuze and Guattari (1987) is used to examine the apparent strength of the threat from a nomadic way of life to settled society (Monbiot, 2022, 2020; McVeigh, 1997).

A post-structuralist interest in discourse can help to deconstruct some of the myths and narratives about Roma people that lead to and support their marginalisation, to address the question as to why Roma people are so marginalised, and to consider the impact of this positioning on discourses about Roma health and well-being. Lipsitz (2007) describes the racially marked national spatial imaginary in the United States, which has underpinned racial segregation throughout its modern history. He contrasts this with an alternative spatial imaginary and discusses powerful discourses that serve to separate racialised groups from majority white communities (ibid.). This focus on space translates to the anxieties of settled communities with regard to nomadism (McVeigh, 1997). There are parallels to be drawn between the story Lipsitz (2007) tells about the racialisation of space and the spacialisation of race in the United States, and narratives that speak of Roma mobility as a threat.

In terms of the locating by van Baar (2018) of the Roma in a nexus between development and security, which is echoed by Robins (1996) in his discussion of the relationship between the people of Turkey and the EU, a further possibility arises in relation to the threat posed by Roma people to western, as well as to CEE countries. Whereas Turkey and its people remain at present outside the EU, the Roma represent a cultural tradition seen as backward and un-modern *within* western European countries, as well as living *within* CEE countries, during the process of adaptation to western capitalist culture (van Baar, 2011a). The mythic threat that the Roma carry is increased by the immediacy of their presence. Romani groups, including Roma communities across Europe, Romanichal Gypsies in the UK, and other Traveller populations, make up a small number of the total population of all European countries (European Commission website, March 2021; World Population Review website, March 2021). Yet, the symbolic power attached to the threat of the nomad appears to be much greater than these mathematical proportions would suggest. Roma people, seeking sanctuary in the West from political threats in CEE countries, have been sedenterised since the 1960s (van Baar, 2011a). Nevertheless, the stigma of their nomadic 'outsider' history continues to create barriers for them, for which they, themselves, are blamed.

A post-structuralist lens offers a way of theorising the symbolic power of the nomadic threat to sedentary, capitalist society. In her study of the health identities of Gypsy and Traveller community members, and of healthcare practitioners, Forster (2018) discusses Deleuze and Guattari's (1987) philosophical concept of nomadology, which takes this thinking beyond the physical world of actual nomadic people, thus capturing the potency of the symbol of the nomad. In the work of Deleuze and Guattari (ibid.), the nomadic represents a condition of existence outside Oedipal regulating control (ibid.). This condition is temporary, other than in an abstract form, as people or ideas are always recaptured by the symbolic order (Lacan, 1991) of language and law. Nevertheless, the nomadic for Deleuze and Guattari is a condition of freedom, both physical and psychic, and of the potential for wildly creative change (Deleuze and Guattari, 1987). Furthermore, the nomad is dangerous and unpredictable, occupying what Deleuze and Guattari call 'smooth space', or space that is 'unstriated', or unstructured and unstratified (ibid.).

A nomadic position is thus the site of profound challenge to institutionalised modes of being: ‘The modus operandi of nomad thought is affirmation, even when its apparent object is negative. Force is not to be confused with power. Force arrives from outside to break constraints and open new vistas. Power builds walls.’ (Massumi, 1987: xiii). It becomes possible to begin to understand how small groups of relatively recently nomadic people, or those struggling to maintain a nomadic lifestyle, might represent a threat not only to sedentarism but to social control itself. A key aspect of the work of Deleuze and Guattari (1987, 1983) was their critique of psychoanalysis, which they saw as operating in the service of repressive processes of recruitment to, and ongoing capture by, the symbolic order. The greatest part of human history was spent living nomadically (Independent Transport Commission website, March 2021; The Independent, 2009); the tradeoff between this and the benefits of land ownership and settled farming may have involved a far greater psychic pain than is currently understood, which perhaps could explain the extreme reaction to nomadism in present day Europe. In her previous work, the present researcher witnessed, again and again, on the part of settled people, a fantasy of a free and unrestricted nomadic life, something very different from the actual day to day lives of Gypsy, Roma and Traveller people.

3.5.3 Voice

Concepts of voice, identity and agency appear less frequently in the literature about Roma people, but their absence is cause for question. As with culture, concepts of voice and identity, from a post-structuralist perspective, critique unspoken notions of an essential or ‘true’ Roma identity and inquire into the nature of the voices of the Roma, thus opening up space for the recognition of the agency of Roma people themselves in engaging with their health and well-being experiences. Howarth’s (2013) theorising of processes of identity and identification, and their relationship with agency and change, is used to examine the findings of the present study, with ideas from the work of Chadderton (2011), and of Barthes (2010), being used to problematise the concept of voice in the context of Roma health and well-being in London.

A post-structuralist concept of voice is not a straightforward matter. As with language and meaning, a post-structuralist conception of voice recognises this, too, as elusive, shifting and subject to the influence of multiple discourses (Chadderton, 2011). Post-structuralist thinking understands individuals as constructing themselves as subjects in terms of the categories or signifiers available to them (Belsey, 2002). The concept of voice in this tradition, therefore, is seen as one in which all voices are subject to the discourses surrounding those who speak (ibid.). All those involved in the present study - participants, researcher, transcriber, interpreters, representatives, gatekeepers and supervisors – brought to the research process understandings derived from the meanings carried within the discourses with which they were familiar. However, discourse, from a post-structuralist perspective is, itself, subject to slippage and change, as meaning is understood to be created within discursive exchange (ibid.). It follows that new meanings and understandings are created through the research process itself (Passerini, 2017).

Post-structuralist research that aims to problematise the oppression of marginalised peoples through creating space for participants' voices cannot, by definition, arrive at a definitive 'truth' about their experiences (Chadderton, 2011). Chadderton (ibid.) draws on the work of post-structuralist theorists to critique attempts to capture an 'authentic' voice, within research aimed at privileging the voices of participants. She identifies the need to recognise the discursively constituted subject, to problematise the relationship between experience and knowledge, and to acknowledge the role of the researcher in generating the data, in order to create more complex notions of voice.

In terms of the impact of the research process itself on the voices of the participants, Barthes (2010: 3) describes the slippage that occurs between the recording of participants' speech and 'scription'. He suggests that this process, which Les Back (2017) notes has become the stock-in-trade of the sociologist, damages the innocence of the spoken word:

> …not that speech is in itself fresh, natural, spontaneous, truthful, expressive of a kind of pure interiority; quite on the contrary, our speech (especially in public) is immediately theatrical, it borrows its turns… from a whole collection of cultural and oratorical codes: speech is always tactical; but in passing to the written word, it is the very innocence of this tactic… that we erase… (Barthes, 2010: 3).

Discourses about Romanes, the Romani language, are rare outside a small academic circle, and the present researcher's previous experience suggested that there is limited awareness in the UK of its existence, in all its variations. Williams (2010: 198) describes the categorisation of languages and cultures, during the development of modernity:

> Languages designated as state languages were deployed for the activities that demanded a capacity to reason – administration, education and science. Other languages were excluded, and were deemed fit only for 'private' use in the home, and perhaps the community, as relevant only for the world of 'tradition'. A distinction emerges between logic and passion, between reason and emotion. It incorporates the classification of

languages.

As modern European states developed, including the post-Soviet states of Central and Eastern Europe, the identity of states coalesced around an officially recognised language and a supposedly unifying majority ethnicity (ibid.).

3.5.4 Identity and agency

Although the complexities of Romani identity have been examined within the relatively closed field of Romani Studies (Marsh and Strand, Eds., 2006; Belton, 2005; Saul and Tebbutt, Eds., 2004; Gheorghe, 1997) and its critics (Matache, 2017), within the European reports and the health literature these complexities were rarely considered. There appeared to be a conflation between Roma culture and Roma identity, resulting in an overall essentialising of the 'cultural identity' (Hall, 1996) of Roma people, notwithstanding some references to diversity amongst Roma groups (National Roma Network, 2017; Brown et al., 2016; McNulty, 2014; RSG, 2012, 2010). However, a post-structuralist concept of identity profoundly critiques earlier notions of identity as an essence, or '…that stable core of the self, unfolding from beginning to end through all the vicissitudes of history without change…' (Hall, 1996: 3). On the contrary, identities are '…strategic and positional…' (ibid: 3). Van Baar (2011a: 104) states that, whilst the debate between the Dutch School and Matras has dominated modern Romani Studies: 'I do not want to suggest that there are no other positions in this debate. Recently, we have noticed a gradual increase of cross-fertilizations of poststructuralist theories of narratology and performativity with issues of Romani identity formation'.

The degree of plasticity and movement accorded to conceptualisations of identity within post-structuralist thinking would suggest a degree of agency on the part of the subject. Within critiques of post-structuralism, however, a frequent assertion is made that its ontology, whereby language rather than the subject is the source of meaning (Howarth, 2013; Belsey, 2002; Hall, 1996), and the subject is formed within discursive practice, leaves the individual subject with no recourse to agency (Howarth, 2013; Hall, 1996). Put very simply, both Derrida and Foucault have been strongly critiqued for positioning the subject, in their theoretical constructions, without the freedom to act (Howarth, 2013; Callinicos, 2007; Gutting, 2005; Hall, 1996). Nevertheless, theorists working with, and developing, post-structuralist thinking offer alternative understandings regarding the relationship between structure and agency and, crucially, processes of identification that constitute a relationship of change between individual subjects and historically contingent discourses (Howarth, 2013; Hall, 1996).

In his analysis of the processes of change, Hall (ibid: 2) calls for a reconceptualisation of 'the subject', which takes account of its displaced or decentred position:

> It seems to be in the attempt to rearticulate the relationship between subjects and discursive practices that the question of identity recurs – or rather, if one prefers to stress the process of subjectification to discursive practices, and the politics of exclusion which all such subjectification appears to entail, the question of *identification* (original italics).

This concept of identification enables the theoretically unresolved question of interpellation, or the process whereby subject formation takes place through a calling into discourse, to be examined from within the post-structuralist tradition. Hall (ibid: 6) is interested in 'the hailing of the subject by discourse', and its relationship with the processes whereby subjectivities are produced. He notes the investment of the subject in the position that they take up and he explores theoretical accounts of the agency of the subject in this relationship. This 'articulation' brings together theories of ideology and discourse on the one hand, and theories of the unconscious on the other (ibid: 6). Hall (ibid: 7) notes the tautology within the critique of the concept of interpellation made by Hirst in 1979: 'It depended, Hirst argued, on a recognition which, in effect, the subject would have been required to have the capacity to perform *before* it had been constituted, within discourse, as a subject' (original italics). There is an understanding here of agency on the part of the individual, as it participates in the formation of its own subjectivity: '…the problematic relationship between "the individual" and the subject. (What *is* the individual "small animal" that is not yet a subject?)' (Hall, 1996: 9, original italics). If subject formation only takes place within the (Lacanian) symbolic register, what are the qualities of a child, in early infancy, that enable it to participate in this process? (ibid.) In addition, if identities can change, what qualities within an adult enable it to choose one discourse over another, during the lifelong process of developing subjectivity?

Hall (ibid.) looks to the work of Foucault (1986, 1985), and of Butler (1993, 1990), both of whom in different ways attempted to bridge this theoretical gap. He discusses the development of Foucault's work (1986, 1985), as he looked beyond, but without abandoning, the centrality of discourse and of law, towards a greater degree of autonomy for the subject. Hall (ibid: 13) notes the gradual emergence of Foucault's analysis '…of the regimes of self-regulation and self-fashioning, of the "technologies of the self" involved in the constitution of the desiring subject'. Foucault was unable, in his analysis, to work creatively with the ideas offered by psychoanalysis, as he saw this '…as simply another network of disciplinary power relations' (Hall, ibid: 14). Butler (1993, 1990), however, combined both Foucauldian and psychoanalytic theory, to examine '…the complex transactions between the subject, the body and identity' (Hall, 1996: 14). Hall suggests that, whilst neither Foucault nor Butler fully resolved this theoretical question, both have contributed significantly to ongoing exploration of this complex analytic territory.

3.5.5 Intersectionality

Several of the newer studies note the need for an intersectional approach to Roma health and well-being, and intersectional experiences of the participants of the present study are considered in Chapter five, as part of the process of analysing the data.

The term 'intersectionality' was first used by Kimberlé Crenshaw, in relation to Black women's experiences of the legal system in the USA (Crenshaw, 1989). Discrimination experienced by Black women could be challenged using anti-sexist legislation, or anti-racist legislation, but there was no linguistic term, or anti-discriminatory legislation, that recognised the totality of the experience of being both a woman and Black. This scenario reflected the fact that the feminist movement at the time privileged the experiences of white women, and the anti-racist movement was focused on the experiences of Black men. Although this double-bind and impossible choice facing Black women had been acknowledged previously, the coining of the term 'intersectionality' enabled experiences of multiple categories of oppression to begin to be thought of, and spoken about, in ways that had not been possible before.

Crenshaw (1991) noted that the delineation of difference, whist often reflecting structures of domination, also offered opportunities for social empowerment and reconstruction through identity-based politics. However, differing categories of identity tended to be viewed as operating in isolation from one another, despite their intersection in people's everyday lives: 'Although racism and sexism readily intersect in the lives of real people, they seldom do in feminist and antiracist practices. And so, when the practices expound identity as woman or person of color as an either/or proposition, they relegate the identity of women of color to a location that resists telling' (ibid: 1242). The outcome of this lack of representation within feminist and antiracist discourses led to the marginalisation of women of colour within both (ibid.).

Crenshaw's work towards giving existence to the locations experienced by Black women led to broader usage of the term 'intersectionality', which was extended to include a range of other social categories. The Scottish Government (2022: 4) notes the experience of '…multiple and compounding inequalities…', in relation to intersectional marginalisation. It is the shaping of one another by differing strands of identity that produces an intersectional experience, rather than the addition of two or more categories of identity or circumstance. In addition, aspects of privilege may also be incorporated into intersectional locations of identity (ibid.). With regard to agency, Crenshaw (1991) points to the possibilities offered by intersectional thinking for coalitions of differently marginalised people to challenge oppression, with the Scottish Government (2022: 7) stressing that: 'Intersectionally marginalised people [should be] viewed as being able to act for themselves'.

Rønn (2022: 6) notes that the concept of intersectionality provides an analytic tool with both theoretical and practical application: '…[T]o develop our knowledge on the relation between sect, class, geography and other identities, we need a common language and systematic analytical approach. It is on this aspect Crenshaw has valuable insights to offer'.

The work of Crenshaw (1991, 1989) along with that of other legal scholars, gave rise to critical race theory, which is '…an academic framework centred on the idea that racism is systemic, and not just demonstrated by individual people with prejudices' (Iati, 2021: 1). Racial inequality is seen as inherent within institutions, such as legal systems, including civil rights and anti-discriminatory legislation, and this acts as a barrier to the eradication of racial injustice (ibid.). Critical race theory acknowledges the social construction of categories such as 'race' and 'gender' but seeks to build on the insights of post-modern constructivist thinking, by privileging political action through identity politics. Whilst deconstructing the meaning of these constructed categories is seen as important, challenges need to look beyond this, to address legal and other structures that uphold and support racism and other forms of oppression (ibid.). In this way, the incorporation of an element of intersectional analysis of the data of the present study builds on, without contradicting, the study's post-structuralist theoretical framework.

3.6 Summary

In this chapter, the theoretical framework used to guide the present study was outlined. A post-structuralist understanding of ontology and epistemology framed the study, with concepts of voice, culture, identity, agency and nomadism being used from a post-structuralist perspective to problematise its findings, in relation to the literature examined. The choice of post-structuralist thinking arose from a reading of the work of van Baar (2011a), whose use of the Foucauldian concepts of governmentality and bio-power opened up understandings of the positioning and representation of Roma people in past and present-day Europe. The health and well-being of individuals and of populations was a key theme within Foucault's work (van Baar, 2011a; McDonnell et al., 2009), and the same topic is a significant aspect of modern European interventions into the lives of Roma people. The present researcher was interested in developing this study, looking at the health and well-being experiences of Roma people in London, using Foucault's broad investigations of health and well-being in relation to power and knowledge, and van Baar's (2011a) wide-ranging study of the Roma as a European transnational minority as a starting point. The work of Howarth (2013), in developing post-structuralist concepts of structure, agency, identity and identification offered further conceptual tools with which to problematise the empirical data collected during the course of the present research. A qualitative methodology was seen to be appropriate within a post-structuralist discussion and this, together with the practical methods applied, is considered in Chapter four.

METHODOLOGY AND METHODS

4.1 Introduction

To answer the research question: **‘To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?’**, a contextual and explanatory qualitative research design was formulated. Chapter four describes the methodology and methods used to carry out the present study. In Section 4.2, qualitative research as an overall methodological approach is discussed, including its ontological and epistemological particularities, and its suitability for use with the concepts chosen for this study, viewed through a post-structuralist lens. The rest of the chapter looks at the methods used, starting with Section 4.3, which outlines the study design, changes made to the study design, its setting, the sampling and recruitment process, and issues relating to interpreting and translation. The use of an open-ended interview schedule is also discussed. In Section 4.4, the process of data collection, using in-depth individual interviews, is described. A critical thematic analysis method was used to analyse the data, and this is outlined in Section 4.5. The relevance of thematic analysis to post-structuralist theory is also considered. Ethical issues are considered in Section 4.6.

4.2 Qualitative research

A qualitative approach to the present study was chosen as this offered the opportunity for rich, in-depth data to be collected, using methods that would allow access to the participant group. The present researcher undertook voluntary work, which contributed to a broader understanding of the cultures, behaviours and beliefs pertaining to this contextual and explanatory qualitative study (Ritchie et al., 2014). At its heart were in-depth interviews with nineteen Roma adults in London, talking about their health and well-being experiences. Ritchie et al. (ibid: 13) note that qualitative research recognises ‘the interrelatedness of different aspects of people’s lives’, and that qualitative research methods can provide a way of seeing human behaviour and beliefs holistically.

Qualitative methods were developed within the social sciences as a reaction to perceived limitations of the earlier emphasis on quantification in the natural sciences (ibid.). Qualitative data was seen to provide contextual information and rich insight into human behaviour, with its methods enabling space for creative and divergent thinking. It also allowed individual experiences to be accounted for, alongside generalisations (Guba and Lincoln, 1994). Ritchie et al. (2014) note that postmodern theory, which includes post-structuralism and deconstructionism, had an important formative influence on qualitative methods in the social sciences in the last 60 years, arising from the critical stance of postmodern theory towards the traditional philosophical assumptions of social research.

Defining qualitative research is not as simple as it might appear, due to the difficulty in locating its position within social science paradigm models. Guba and Lincoln (1994: 105) suggest:

> Although the title of this volume, *Handbook of Qualitative Research*, implies that the term *qualitative* is an umbrella term superior to the term *paradigm* (and, indeed, that usage is not uncommon), it is our position that it is a term that ought to be reserved for a description of types of methods… Questions of method are secondary to questions of paradigm…

They also state (ibid: 105): ‘From our perspective, both qualitative and quantitative methods may be used appropriately with any research paradigm’, and Denzin and Lincoln (2011: 6, cited in Ritchie et al., 2014: 2) note: ‘Nor does qualitative research have a distinct set of methods or practices that are entirely its own’.

Ritchie et al. (ibid: 3) note the ‘wide range of [qualitative research] approaches and methods found within different research disciplines’. They suggest that qualitative research is interpretative, studying things in their natural settings and seeking to explore phenomena from the perspectives of research participants. They also identify a focus on processes and note the flexible nature of qualitative research design. Qualitative research tends to focus on words or images, rather than on numerical data, and its data can provide volume and richness. Hypotheses tend to be generated from analysis of the data, rather than data being gathered to confirm an a priori hypothesis (ibid.).

Jennifer Mason (2017: 29) describes the need within qualitative research to build a convincing analytical narrative based on ‘richness, complexity and detail’, rather than on statistical logic. She points out that qualitative research is ‘more of an ideographic approach, where you build a broader argument from an understanding of particularity’ (ibid: 30) and notes the need to build in sufficient variation to allow exploration of a range of responses to different circumstances. However, Mason (ibid: 30) points out that, ‘you will not argue that your interviewees “represent” similar categories of people in the wider population’.

An important aspect of qualitative research, from a critical postmodern and post-structuralist stance, is reflexivity on the part of the researcher (Ritchie et al., 2014). Post-structuralist research is interested in the range of culturally produced discourses informing understandings of the topic being studied. As well as discourses impacting on the experiences of research participants, those influencing the position of the researcher, in terms of the reasons for the choice of study topic, and the researcher's relationship to the participants and to the analysis and presentation of the data, also form part of the total picture of the research outcomes.

In terms of the story told by the researcher, Chadderton (2011: 5) notes the influence of the researcher's beliefs, values and prior understandings, and the effect, on the data that is produced, of the way she is positioned by the participants: 'Therefore, it could be argued that she does not collect data so much as generate it through her own involvement'. Nevertheless, participants are not without power in this process, and may, '…resist the research process, by resisting certain avenues of questioning, leaving their meanings unclear, contradicting themselves and hiding things, telling different stories to the ones for which they are asked' (ibid: 7). Luisa Passerini (2017: 32) focuses on '…intersubjectivity as the constitutive element of qualitative interviewing', again, problematising any simplistic notion of voice. She suggests that '…the interview was created by the encounter between two or more persons, and the effects of their intersubjectivity should be pointed out. Certain questions were asked, and not other ones; certain replies were given, and on other points there was silence' (ibid: 32). Anthony Howarth (2015) draws attention to the need for researcher reflectivity to include a consideration of changes to the researcher's subjectivity, as a result of participating in the research process. For this reason, following the conclusions (Chapter seven) of this study, there is a reflection (Appendix A) by the present researcher, regarding positioning and the experience of completing the study. Howarth, whose work is in ethnography, critiques anthropological accounts of positionality, based on categories such as gender, ethnicity and class, which he suggests do not account for the very complex and transitory nature of the subjective self in more reflexive research.

4.2.1 Ontology and epistemology in qualitative research

Guba and Lincoln (1994: 108) note that a paradigm is a basic belief system that represents the worldview of its holder and see all paradigms as human constructions: 'No construction is or can be incontrovertibly right; advocates of any particular construction must rely on *persuasiveness* and *utility* rather than *proof* in arguing their position' (original italics). O'Gorman and MacIntosh (2015: 61) point out, as does Acton (2012), that Popper, whilst arguing strongly for the adoption in social research of the conventions of science, stresses that, 'sociologists must […] embrace the point that there are no such things as 'truth' other than conjectural, relative truth'. Nevertheless, Acton (ibid.) suggests that recognising that an absolute truth is unobtainable is not incompatible with the scholarly desire for rigour, the value of which should not be underestimated or lost in a relativist academic environment.

Guba and Lincoln (1994: 108) describe three fundamental and interconnecting questions that they believe must be answered in order to construct a research paradigm. These relate to beliefs about ontology ('What is the form and nature of reality and, therefore, what is there that can be known about it?'), epistemology ('What is the nature of the relationship between the knower or would-be knower and what can be known?'), and methodology ('How can the inquirer (would-be knower) go about finding out whatever he or she believes can be known?'). They state that, 'The methodological question cannot be reduced to a question of methods; methods must be fitted to a predetermined methodology'.

The present qualitative study sought new understandings about the experiences of Roma people living in London, in the area of health and well-being. In order to claim that the findings of the study constituted new knowledge, the question of how this claim might be substantiated had to be considered. What is knowledge, how can knowledge be obtained, and in what circumstances, if any, might knowledge be taken to be 'true'? Social scientists holding a range of theoretical positions suggest that these questions cannot be answered independently of a consideration of beliefs about ontology, or the form and nature of reality (Archer et al., 2016; Bhaskar, 2014; Howarth, 2013; Guba and Lincoln, 1994). Writing about critical realism, Archer et al. (2016: 6) state:

> Historically, social science, rightly seeking to ground itself in empirical investigations, has paid attention to epistemology at the expense of ontology – that is to say, sociology has focused on how we know what we know, while questions about the nature of the known are largely treated as an afterthought. The result has been a focus on methods and forms of explanation, with insufficient (or naïve and misguided) attention to questions about what kind of entities actually exist in the social world and what they are like. This has often left sociology with what amounts to be an implicit realism when it comes to empirical data, an unexamined relativism when it comes to forms of explanation, and a certain skittishness to any claims about the nature of the world.

Working within a Kantian philosophical framework, Ritchie et al. (2014: 4) consider philosophical issues in relation to social research: 'Key ontological questions concern whether or not there is a social reality that exists independently of human conceptions and interpretations and, closely related to this, whether there is a shared social reality or only multiple, context-specific ones'. They focus on the traditional Western binary between realism and idealism, noting the realist differentiation between the world itself and the interpretation of the world by human beings; and the idealist view of reality as fundamentally mind dependent. They note that a key question for all social research paradigms is that of the nature and degree of human agency, and they stress the importance of socially constructed meanings within the idealist position. Ritchie et al. (ibid: 24) suggest that qualitative research methods can be used with any research paradigm and conclude that, as a result, '[q]ualitative researchers vary in their ontological stances but there is a common understanding that the social world is governed by normative expectations and shared understandings and hence the laws that govern it are not immutable'.

In their discussion of the foundations of qualitative research, Ritchie et al. (ibid.) locate post-structuralism and deconstructionism under the broader heading of postmodernism, along with theories grouped together under the umbrella term, critical theory. They do not discuss the very particular relationship that post-structuralist thinking has with ontology. Regarding post-structuralism, Howarth (2013: 21) states that 'ontological questions are an unavoidable part of any social inquiry and must therefore be addressed and clarified'. However, post-structuralist thinking sees all ontological positions as culturally and historically contingent, with the notion of representation itself also being historicised (ibid.).

Similarly, Ritchie et al. (2014) discuss epistemology within social research, and within qualitative research specifically. They consider debates about the ways in which knowledge should be acquired, using inductive or deductive processes; the relationship between the researcher and the researched and, 'how this influences the connection between "facts" and "values" (ibid: 8); and issues regarding truth claims. Ritchie et al. (ibid.) also consider the opposition between positivism and post-positivism, and interpretivism and constructivism. They connect early ideas regarding qualitative research with the work of Kant (1781), William Dilthey (1860s-1870s), and Max Weber (1864-1920). All of these thinkers, in different ways, were interested in human beings' interpretations and understandings of their experiences of the world. Dilthey was interested in human agency and in the social, cultural and historical contexts in which people lived (ibid.). Weber believed that the material conditions in which people lived should not be forgotten, but that researching the human social world was qualitatively different from research in the natural sciences, where fixed laws were believed to govern all phenomena (ibid.).

This focus on interpretation and understanding, and context, within social research led to the development of interpretivism and constructionism, in which knowledge was seen as actively constructed by human beings (ibid.). Ritchie et al. (ibid: 13) state that:

> Both approaches reject the idea of ‘value neutral' observations and universal laws, and both focus on understanding lived experience from the points of view of those who hold it. This interrelatedness of different aspects of people’s lives is another important focus of qualitative research and psychological, social, historical and cultural factors are all recognised as playing an important part in shaping people’s understanding of their world. Qualitative research practice has reflected this in the use of methods which attempt to provide a holistic understanding of research participants’ views and actions in the context of their lives overall.

In summary, Ritchie et al. (ibid: 24) suggest that ‘[q]ualitative research is largely associated with interpretivism’.

Once again, though, post-structuralist epistemology challenges the view that meanings and understandings are created through human perception, seeing meaning as being carried within the discourses of language. The source of meaning, for human beings, lies within the symbolic order, defined by Lacan (1991) as the shared experience of language and law that holds human societies together, rather than within the mind of the individual. However, despite post-structuralism’s differing position in relation to traditional Western philosophical beliefs, a qualitative research approach is still appropriate with a post-structuralist theoretical framework for several reasons. Post-structuralist thinking challenges any notion of essentialist or absolute laws governing meaning in the human social world, seeing meanings as culturally and historically contingent, and disagrees with the positivist belief that it is possible to take up an objective position as a researcher (Howarth, 2013). In common with many other qualitative research paradigms, post-structuralism seeks understanding of human experience, through its particular focus on discourse and ideology. Reflexivity on the part of researchers using post-structuralist concepts, in terms of discourses impacting on their own thinking, as well as discourses influencing research participants, forms a central aspect of the research process. In the case of the present study, the researcher, as the research unfolded, was interested in the impact of culturally and historically contingent discourses, narratives and ideologies on understandings of the health and well-being experiences of Roma people living in London.

Using a theoretical framework that aimed to problematise the concepts of voice, culture, identity, agency and nomadism derived from post-structuralist thinking, together with a qualitative research methodology, the researcher selected appropriate methods for the present study. The overall study design is outlined below.

4.3 Study design

4.3.1 Type of study

The present study was informed by ontological and epistemological understandings derived from post-structuralist discussions. The fieldwork tool used within the study was semi-structured in-depth individual interviews. Kallio et al. (2016) note the need for rigour when carrying out and reporting on qualitative research, whilst suggesting that a semi-structured interview guide offers versatility and flexibility and enables '…reciprocity between the interviewer and participant' (ibid: 1). The interviewer is able to ask follow-up questions, based on the responses given by the participants, and space is offered for participants' voices and views to be fully expressed (ibid.) A semi-structured interview guide presents the main topics of a study to the participants, but there is flexibility for both researcher and participants to follow lines of thought that are particularly salient (ibid.). This was very much in line with the approach of the present study, and a semi-structured interview guide was devised, which drew on previous knowledge of the topic area, such as that gained from carrying out the initial literature review, as well as the present researcher's experience as a volunteer, to frame the interview conversations around aspects of health and well-being considered likely by the researcher to be significant to the experiences of the participant group.

This was a contextual and explanatory qualitative study. It was intended that the findings would be both descriptive and explanatory (Ritchie et al., 2014), allowing space for personal accounts, which would provide the basis for exploring a range of interconnecting discourses relating to the health and well-being experiences of Roma people in London. The study was cross-sectional, looking at the experiences of its group of 19 participants, drawn from the Roma population in London at a particular point in time, in order that the participants' experiences might be compared (ibid.). Ritchie et al. (ibid.) note that a single cross-sectional study looks at one participant group at a specific time, whereas in a longitudinal study the same people are interviewed more than once, over a longer period. The findings of the present study described what was reported by the participants, whilst being interpreted by the researcher (ibid.). Further insights into the participants' experiences were gained, using the theoretical lens of post-structuralist concepts, and both aspects informed the development of guidelines for the practical application of the findings in the UK healthcare context. Reflexivity on the part of the researcher was a constant and essential aspect of all stages of the study and was an integral part of the epistemological approach to the data analysis. Changes made to the initial proposal for the study design are described below.

Changes to the study design, rationale and implications

The initial proposal for the present study was for a mixed methods approach, including both qualitative individual interviews and a quantitative survey tool. However, as the study progressed, the present researcher in discussion with her supervisory team decided to focus solely on a qualitative methodology. It was agreed that recommendations based on the findings from analysis of the individual interviews would form the basis of guidelines for healthcare professionals, and that a quantitative survey tool was not an appropriate outcome from these findings, in the context of the present study's focus on narrative, discourse and the voices of its participants.

Ritchie et al. (2014) discuss the centrality of aligning the objectives of a study, and the nature of the data required to meet these objectives, with appropriate research methods. The present study set out to answer the research question **'To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?'.** The study was framed within post-structuralist theoretical ideas, and was focused on the experiences of its participants, told through their own voices. The data from the individual interviews represented the voices of the Roma participants, resulting from storytelling about their experiences. The post-structuralist lens of the study focused on language use, and allowed the experiences recounted by the participants to be examined in relation to wider discourse and narrative about Roma health and well-being.

The outputs of the present study resulted from analysis of the findings of the in-depth individual interviews. In addition, the decision to use a qualitative methodology only, and to produce guidelines for healthcare professionals, significantly focused on language use, rather than a survey tool, was supported by both theoretical and practical considerations. Whilst learning of the depth of qualitative research, and analysing the data from the individual interviews, the present researcher realised that a survey tool would be completely incompatible with the methodology and focus of the study. It seemed contrary to the nature of this qualitative data to translate it into a quantitative survey tool and, more broadly, contrary to the spirit of the study itself.

Ritchie et al. (ibid.) note that, although mixed qualitative and quantitative methods are nowadays commonly used in social research, debates about both logic and process in combining results continue. Not only do ontological and epistemological issues arise, but there are also questions regarding the privileging of one method over another, and doubts that mixed or multiple methods necessarily provide a more certain picture of the subject under consideration (ibid.). Mason (2017) points to the very different approaches offered by qualitative and quantitative research methods, which she describes as an opposition between narrative and logic.

Given the need for methods to fit with the objectives of research, and the present study's focus on the depth of experience of its participants, an interpretative approach seemed to provide the best fit. It was unclear as to how statistical data, produced by a survey tool, would benefit this focus, or how two such different types of data might be combined within a post-structuralist study of storytelling, narrative, and discourse. In terms of policy implications, the initial literature review showed a focus within European policy documents on structural issues, discrimination and Roma culture. In the UK, the literature showed a similar focus, while there was little evidence of substantive policy. There was clearly space for the development of UK policy regarding Roma health and well-being but, whatever the contribution of the present study, its outcomes needed to fit closely with its specific focus and theoretical stance.

This was a contextual and explanatory qualitative study. It was intended that the findings would be both descriptive and explanatory (Ritchie et al., 2014) and that guidelines for healthcare professionals, focused on the experiences of the participants and the use of language in relation to Roma health and well-being, would be an appropriate, original, and potentially useful outcome of the present study. The researcher liaised with her local health authority, comprising three southeast London boroughs, in order to develop draft guidelines. This process involved initial consultation with a mental health service, in connection with their work with the diversity officer of one borough. Feedback from this consultation allowed draft guidelines to be developed with a view to their inclusion in local NHS diversity policy (Appendix P).

In addition, findings from the initial literature review, voluntary work undertaken by the researcher, and from the individual interviews suggested potential practical difficulties in relation to creating and conducting a quantitative survey. Access to participants for the individual interviews was dependent upon gatekeepers, interpreters and, in some cases, other representatives. As well as questions about purpose, recontacting the original participants, or a wider group of participants, would have presented sampling and access issues for the researcher, and communication difficulties, both oral and written, as well as issues regarding digital access for participants. The involvement of gatekeepers, interpreters, translators, representatives, and transcriber already generated a gap between the participants' voices and the analysed findings, which is discussed in section 4.3.5. The use of a statistical survey tool would have further complicated the relationship between the researcher and the participants' stories, without providing any clear compensation for this. Also, further demands made on gatekeepers and interpreters might not have been met with the initial helpfulness experienced by the researcher. A wider group of participants accessed for a statistical survey could have altered the geographical area of the research, leading to questions about the usefulness of additional data and combining the results of the two methods.

The participants did not show a wish to pursue further engagement with the study, including the possibility of participation in focus groups, and this was respected. Ritchie et al. (ibid.) note that subject matter that is difficult to address through structured surveys may be more suited to qualitative methods, and that this may include sensitive matters that could be distressing for participants. Whilst focus groups can offer opportunity for sharing otherwise isolating experiences (Babatunde and Moreno-Leguizamon, 2012), discussion of sensitive issues, such as health and well-being matters, can also be inhibited in such groups (Ritchie et al., 2014). The present researcher's experience as a volunteer, as well as the findings of the initial literature review, suggested that, in addition to generic sensitivities around matters of health and well-being, Roma cultural taboos may also inhibit participants from speaking about their experiences. Under data protection legislation, the Roma participants were considered to be vulnerable subjects and individual interviews in a known environment with familiar interpreters and representatives appeared to offer a more relaxed setting for the study's participants to talk about their health and well-being. Ethical issues regarding working with vulnerable subjects, recruitment, changes of output, use of gatekeepers and the role of the transcriber are discussed further in section 4.6.

Using a semi-structured interview schedule

The researcher carefully considered the reasons for choosing an open-ended question schedule to interview the Roma participants. In relation to carrying out fieldwork, specific approaches to research undertaken with members of Gypsy, Roma and Traveller groups have been described by D'Arcy (2014), Acton (2007) and Goulet and Walshok (1971). Approaches that take up an empathetic position towards Gypsy, Roma and Traveller research subjects, such as those of Goulet and Walshok (ibid.) and D'Arcy (2014), appeared to offer positive models. However, these approaches seemed to assume that the educational levels of Gypsy, Roma and Traveller research participants, and their construction as 'marginalised', would lead to a lack of understanding on the part of the participants, with a resulting need for simplification of, for example, interview material. These ideas were considered when devising the interview schedule for the present study.

A key aspect of the approaches of Goulet and Walshok (1971) and of D'Arcy (2014) was the use of interview schedules using open-ended questions. Acton (2007) notes that attitudinal questions were first used by Goulet and Walshok (1971), who interviewed Spanish Gypsies in 1967- 8. Acton (2007: 4) points out that, 'It used to be part of the received wisdom that questionnaires would never work in research on Gypsies'. Acton (ibid.) suggests that, although Hoyland, in 1816, had used helpers to ask questions of English Gypsies, this had resulted in an outsider's view of Gypsy culture, rather than capturing the views of Gypsies themselves. When researching the lives of members of communities other than one's own, the concepts of insider and outsider are useful in considering both an appropriate and a sensitive approach, and in understanding the interactions between researcher and participants (Bhopal and Myers, 2008). Bhopal and Myers examine in detail ideas about insiders and outsiders, in relation to Gypsies in the UK. Much of what they discuss is relevant to the wider Romani collectivity, including European Roma. Using Bauman's (1991) notion of the 'stranger', they consider the ways in which Gypsies are constructed as 'other', to a degree that seems to go beyond the 'othering' of most communities. Bhopal and Myers (ibid.) refer to the powerful cultural boundaries that exist between Romani and non-Romani groups, and which are maintained on both sides, and note the impact this has on the construction of identity of both groups. It was important to devise fieldwork tools that would be respectful of the Roma community, accessible to the participants, and would enable these boundaries to be crossed to some degree, in order to allow the participants to speak about their experiences.

Goulet and Walshok's (1971) description of their work with Spanish Gypsies offers their perspective on devising a methodological approach to research with members of communities who are economically and politically disadvantaged and, more importantly, constructed as 'marginal'. Working within the development field, they challenged the prevailing view of the time, which, 'either ignore[d] values or treat[ed] them instrumentally' (ibid: 452). They wanted to understand how members of such communities might see the relationship between their own values and the images they held of the benefits commonly associated with development, such as improvements in housing, nutrition, jobs and education: 'The human values of the populace at large are treated too often simply as raw material to be processed for the obtention of goals whose own value is given' (ibid: 452). Although not described in post-structuralist terms, there is an awareness here of the impact of discourses on research outcomes, and on the resulting value placed on the views of research participants.

After encountering a range of difficulties in gaining access to the particular Spanish Gypsy communities with whom they wished to undertake their investigations, Goulet and Walshok devised a series of questions, which was then revised several times before being recast in the form of seven key words. Goulet and Walshok (ibid: 460) state that, 'Interviews flowed freely after the key-words format was adopted. More significant, certain topics not originally included amply stimulated self-revelation on the part of Gypsies'. Goulet and Walshok suggest that 'Strong confirmation of Caillot's injunction was obtained; namely, that any population studied must be the principal architect of the instruments by which it is studied' (ibid: 460).

In a similar vein, Kate D'Arcy's (2014) study of the use of Elective Home Education by Gypsy and Traveller families in England includes a thoughtful analysis of the research process in relation to marginalised groups. Drawing on approaches used in New Zealand for research with Maori communities, D'Arcy discusses the process she used for choosing her data collection methods. Given the strong oral tradition of communication within Gypsy and Traveller communities, D'Arcy chose interviews as an appropriate way to collect data, and one that would allow her, 'to attend to Gypsies' and Travellers' own voices' (ibid: 68), as opposed to, 'a questionnaire format [that] would not invite rich descriptions of individuals' experiences and views' (ibid: 69). Referring to the work of Burman (1994) and of Clough and Nutbrown (2007), D'Arcy (ibid.) notes the importance of using her interview schedule as a guide, rather than a directive, when conducting her interviews. She stresses the need for the researcher to be flexible when following an interview schedule, in ensuring that participants are not intimidated.

Given the diversity amongst Romani groups more widely, it cannot be assumed that all research participants in these groups need a simplified approach. However, enabling research participants to feel secure and comfortable when speaking to a researcher might be better seen as a positive approach to all research, with participants from all communities. Where participants are asked to talk about personal experiences, often with a researcher previously unknown to them, an open-ended interview schedule offers space to do so in all qualitative research contexts. An open-ended question schedule was devised for the present study on this basis.

In order to ensure the trustworthiness of the present study, Guba's (1981) criteria, as described by Shenton (2004), were considered. Shenton (ibid.) notes that Guba suggested four domains for consideration: credibility, transferability, dependability and confirmability. Taken together, these can provide a good degree of trustworthiness, in relation to qualitative research, the attributes of which are, by definition, not measurable. Appendix O shows the steps taken to demonstrate the trustworthiness of the present study.

4.3.2 Setting

In order to answer the research question, the empirical research for the present study was carried out in London. London was chosen as an appropriate setting for the study because Roma people in the UK tend to live in cities, where access to casualised work is more readily available, and London was seen as a setting that could offer realistic opportunities to pursue a rich and detailed study.

A sample frame was generated for the study through contacts made by the researcher with gatekeepers at three organisations working with Roma people living in three northeast London boroughs (Ritchie and Lewis, Eds., 2003). These comprised two Traveller Education Services (TES), and one charity supporting and advocating for Roma communities through a wide range of projects. Access to nineteen self-identified Roma research participants was facilitated by staff of these organisations.

Through extensive previous work in Gypsy, Roma and Traveller Education in London, the researcher had many contacts within this field. However, at the time of the study, cuts to local authority funding had led to the closure of many TES, thereby reducing the number of organisations working directly with Roma individuals or families in London. In this context, the researcher's contacts were seen as essential in contacting a relatively diverse group of potential participants, and in establishing trust.

The researcher approached a senior member of staff within each of these organisations, each of whom was known to her through her previous work. These members of staff acted as gatekeepers between the researcher and the selected participants, facilitating interviews with participants who met the selection criteria described below. One of the gatekeepers also acted as a representative for four participants. In the case of a second organisation, a member of staff who was not the gatekeeper acted as representative for one participant. This representative was also a participant in the study.

Written information about the present study was provided for all the organisations that were approached (See Appendix G). Thirteen participants were interviewed in three professional settings, five participants were interviewed in their own homes, and one was interviewed in a coffee shop. The interview process is discussed below in section 4.4.1.

4.3.3 Sampling

An opportunistic sampling method (Ritchie and Lewis, ibid.) was adopted. Ritchie and Lewis (ibid: 81) state: 'Opportunistic sampling involves the researcher taking advantage of unforeseen opportunities as they arise during the course of fieldwork, adopting a flexible approach to meld the sample around the fieldwork context as it unfolds'.

Opportunistic sampling is a non-probability or non-random sampling technique that does not give all participants in the relevant population an equal chance of being included in the study, but which is suited to small-scale, in-depth qualitative studies. A non-probability sample is not designed to be statistically representative; instead, participants are selected based on specific characteristics of the study population (ibid.). Ritchie and Lewis (ibid.) note the need within qualitative research for a different logic from that used in quantitative enquiry.

The sample frame was created through contact with gatekeepers at three organisations working with Roma people in northeast London. Through approaching TES, as well as a charity, it was intended that the sample group would include participants with a wide range of health and well-being experiences. Ritchie and Lewis (ibid: 83) consider the precision and rigour of a qualitative research sample to be dependent on the degree to which it represents salient characteristics of the subject matter, or 'symbolic representation'. They also note the need for diversity within the sample, to provide for greater opportunity to identify contributing factors, as well as the interdependency between concepts. They suggest (ibid: 82) that '…the principles of probability sampling can work against the requirements of sound qualitative sampling'. Participants were included on the basis that they were self-identifying Roma adults (aged over 18), living in a London borough, and known to the gatekeeping organisation. Nineteen participants were deemed to be sufficient for the present qualitative study, focused on the depth of data generated through its semi-structured interviews, with a group of nineteen people seen as intrinsically complex and heterogeneous.

Goulet and Walshok (1971) suggested that, when undertaking research with members of marginalised communities, especially where access to formal education has been limited for community members, individuals who do take part are likely to be those with more experience of the dominant cultures, and with less resistance to interaction with researchers from these cultures. In this respect, Goulet and Walshok (ibid) described members of communities who were subject to development programmes as 'traditionals' and 'transitionals'. When interviewing Spanish Gypsies in the 1960s, the small number of respondents to their much-adapted question schedule were all said to be 'transitionals', prompting them (ibid: 461) to state:

> We are therefore led to ask: Do 'traditionals' in other societies also lie beyond the reach of interview instruments? Do those who use such instruments mistakenly assume that respondents are 'traditionals' when, in fact and from the very nature of the case, information can only be obtained by such means from people who have already become 'transitionals'? This question, in our view, merits further attention.

The terminology used by Goulet and Walshok (ibid.) is old-fashioned and would nowadays be considered inappropriate, and such unsophisticated classification both prejudges the participants and presupposes the outcomes of research. Nevertheless, the question raised by Goulet and Walshok (ibid.) regarding the make-up of any research participant cohort is relevant to the outcomes that can be drawn from it. In relation to the present study, the complexity within a group of nineteen participants suggested the probability of finding heterogeneous views about social change, religion, gender, ethnicity and so forth. Even within a nuclear family, not all members share the same views. Thus, heterogeneity is a given in any group, rather than being something sought by a researcher. In the case of the present study, the criteria for inclusion were kept flexible and open. In terms of potential participants approached, factors including time available, dependence on facilitating agencies, and the availability of interview venues and interpreters, all contributed to determining who was, and who was not, included in the participant group.

It was decided that the focus for the present study should be to facilitate interviews with Roma community members who had made positive and active relationships with Gadje (Roma word meaning non-Roma people) staff of the organisations contacted when seeking research participants. Engaging with Roma individuals met trading or begging on the streets, with limited or no English, would be much more difficult and time-consuming, although their omission could significantly change the ultimate picture drawn by the analysis of the data.

4.3.4 Recruitment

The approach described above allowed the researcher access to Roma individuals living in London and overcame potential difficulties in terms of language. The coordinators of the TES agreed to facilitate introductions to parents of Roma children with whom they worked. Other adult relatives of these parents were also invited to take part in the research. In addition, between July 2016 and February 2017 the researcher undertook once-weekly voluntary work for the charity working with Roma communities, in exchange for introductions, with the researcher carrying out a range of desk-based tasks in support of a mental health project run by the charity. The researcher made this choice as it would offer insight into this innovative project and the views of the recipients of this work. A Disclosure and Barring Service (DBS) check was required by the charity for all staff, including volunteers, and this was undertaken.

Between October 2016 and February 2017, sixteen participants were interviewed. A further three participants were interviewed between January 2018 and June 2018. Nine of the participants had come to the UK as asylum seekers, whilst seven had arrived under EU freedom of movement regulations, following the accession of the A8 and A2 countries. Two participants, who were sisters, had come from non-EU European countries, and had been in the UK for 20 and 11 years, respectively. In one case, the participant did not give information about their immigration status. Of the nineteen participants interviewed, three had obtained British citizenship. Others had residency permits or were in various stages of application for these.

Thirteen women and six men were interviewed. The ages of the thirteen women ranged between 20 and 65 years, with three participants preferring not to state their age. The six men were aged between 19 and 33 years; one, who was a grandparent, chose not to state his age. Eleven of the participants had children, and two had school-aged siblings. In seven cases, participants' children had been born in the UK and one participant had eight grandchildren, all born in the UK. In three cases, children's ages were not stated, and their place of birth was not known to the researcher. One participant was pregnant at the time of the interview, and her baby was due to be born in a local London hospital. Three of the male participants had no children, one female participant had no children; in three cases, no information was given regarding family composition.

4.3.5 Interpreting and translation

Interpreters and translators were recruited to facilitate the collection of data. Although the first language of most, if not all, of the Roma participants in the present study was a version of Romanes, the Romani language, where necessary interviews were carried out with the help of an interpreter speaking the language of the participant's home country (See Table 1). In a peer support group meeting attended by the researcher, Roma clients at the charity had made clear that they preferred not to discuss health and well-being issues with a Roma interpreter. Many taboos exist in Romani culture regarding discussion of issues to do with health and, in particular, mental health, as well as strictly observed gender divisions. It was suggested that, to discuss health issues in the presence of another Roma community member, could lead, in some instances, to ostracism from the community. It would also be impossible, for example, for a woman to discuss aspects of female health in front of a Roma man. Disclosure of health issues could be seen as problematic for all people in all communities, particularly to a previously unknown researcher. It was recognised that health and well-being can be a sensitive topic in all contexts, with the presence of an interpreter potentially adding to these issues, and that Roma people were aware of their own cultural difficulties in this context.

The use of the language of the home country may not have been the preference of every Roma individual interviewed, but the researcher decided to follow this practice for the present study. Even if Romanes had been preferred in some cases, its wide degree of variation, even within one country, would have made arranging interpreters very problematic, to capture this further complexity. Arranging interpreters speaking the languages of the countries from which the participants had moved, offered both a culturally appropriate and practical option.

In addition to the need for interpreters to facilitate several of the interviews, the information for participants and the participant consent form also needed to be translated into the main relevant languages. These documents were initially submitted in English, as part of the application for ethical approval. Later, the information for participants and the participant consent form were translated into Polish and Romanian, these being the languages of the countries of origin of the majority of the participants (See Appendices H, I and J: Information for participants; and Appendices K, L and M: Participant consent form). In October 2016, an application for funding for essential interpreting and translating services was made to the University Resources Fund, and this was granted.

The present study was both interested in language use and significantly mediated by interpreting and translation processes. English, the language of the present study, was not the first language of any of the participants. Where requested by a participant, all or part of the interview was mediated by an interpreter who, also, was not a first language speaker of English. The first languages of the interpreters were the second languages of the relevant participants. Where representatives were present, one was a first language speaker of English, which was one participant's second language and the other participants' third. In the other case, the representative and the participant shared the same first and second languages. The researcher was not a speaker of the first languages of the participants, or of the first languages of the interpreters or of the first or second of one representative. The transcriber of the interview recordings was a first language English speaker, living for many years in another country and bi-lingual, but not in the languages spoken by the participants, interpreters or one representative of the present study. The first supervisor of the present study was also not a first language speaker of English but was teaching in an English university. The complexities of working with this wide range of languages was, nonetheless, a strength of the study, as it offered varied perspectives on the topics discussed. Kapborga and Berterö (2002) suggest that the potential for mistranslation and misinterpretation is a threat to validity, where researchers are reliant on the accuracy of interpreters' translations. However, within the post-structuralist tradition, which includes discourse analysis, validity is determined by the reader's own engagement with the text (Belsey, 2002). Wechsler (2016: 1) describes her decision to use interpreters with participants who spoke a moderate amount of her own language:

> '…because I wanted to ensure that they could express themselves in a nuanced manner. Furthermore, I wanted these participants to be able to focus on the substance of the

> interview rather than on finding the right words to articulate their thoughts in a language in which they were not entirely comfortable'.

In the case of the present study, this strategy was used by participants themselves, who chose whether or not an interpreter should be available for their interview. Interpreters who took part in the present study were known to the participants, thereby facilitating rapport (ibid.).

4.4 Qualitative research data collection

4.4.1 In-depth individual interviews

Interview topics

A semi-structured schedule using open-ended questions was designed for the individual interviews, as this would provide a range of in-depth data that could be compared across the data set (Ritchie et al., 2014). The questions were informed by the findings of the literature review and the contextual material examined, both historical and contemporary, but these findings could not be taken to be definitive. The approach to the fieldwork chosen for the study sought to accommodate the wide diversity amongst Roma people. The questions were devised to avoid any suggestion of 'correct' or 'incorrect' answers, and to allow participants to develop their responses in ways that they believed to be the most significant to the questions. Whilst it was acknowledged that, from a post-structuralist perspective, the literature could not be viewed as definitive or 'true', its contents provided a framework for the interview schedule. This allowed participants space to take the conversation in directions of their choosing, whilst retaining an overall focus for the cohort on what were likely to be significant aspects of health and well-being. The following overview outlines the topics covered by the interview questions. (For the full, revised semi-structured interview schedule see Appendix E.)

Topic One – General use of healthcare and well-being services

General experiences – opportunity for participant to open with any aspect of their experience

Experiences in country of origin or other countries

Barriers to access

Impact of migration

Comparison between Roma culture and UK mainstream culture

Topic Two – Specific aspects of healthcare and well-being services

Maternity services, infants and children

Care of the elderly

Roma healthcare in previous generations

Mental health and well-being

Smoking and childhood hearing impairment

Improvements to services and experiences

Topic Three – Other aspects of health and well-being care / Clarifications

Opportunity for participant to add further contributions to the conversation

Opportunity for participant to clarify points made, or to request clarification from the researcher

Changes made to the interview schedule

Early in the process of collecting the data, in discussion with the present researcher's supervisor, it became clear that some of the questions were too complex, and the researcher found it difficult to explain what was being asked. By the fifth interview, revisions had been made to the schedule. In the first group, the questions were reordered, so the topics flowed from one to another in a more understandable way. Questions about the possible effect of the participant's immigration status on their health and well-being experiences, and about potentially different views of health and well-being in Roma and non-Roma cultures, were simplified. Slight changes were made to the wording of other questions, to make them more direct and personal.

In the second group, a confusing introduction was simplified, and two questions about child development and pregnancy and childbirth were combined, for added clarity and to allow for aspects of the question to be avoided without causing embarrassment to the participant. A question about the care and well-being of elderly people was altered, to omit asking about end-of-life care. The researcher felt that this was too direct and that participants would be able to talk about it, should they wish to do so. A question about Roma healthcare in previous generations became the next question asked; again, this produced a more direct link between topics. Initially, the researcher had included a question about caring for physical needs and the body, as a contrast before asking about caring for emotional needs and feelings. This was removed as it was difficult to answer, but the contrast was noted by the researcher in introducing the question about emotional needs. The word 'stress' was added to this question, as a prompt to understanding. Two new questions were added, seeking participants' views about health professionals' opinions drawn from the literature. A question about possible improvements and the potential for Roma people to make their experiences of services better for themselves was added at the end of this group of questions. The questions in the third group were unchanged. After making the revisions, the researcher added topic summaries, in colour, next to each question, to facilitate her own grasp during the interviews of the purpose of each. Following these changes, the researcher found the interviews more manageable and felt that they flowed more easily.

In terms of the epistemological position taken in relation to this study, and post-structuralist theory more generally, this approach recognises the fact that a range of discourses and understandings are likely to be informing and influencing both the participants' responses, as well as the researcher's interpretations, and it aims to allow space for these. Post-structuralist theory understands meaning as contingent, and historically and culturally constructed. There could be no definitive answers to the questions asked and no assumptions made, including the assumption that Roma people are necessarily having negative experiences regarding health and well-being in London. The researcher needed to be highly reflexive regarding her own viewpoints and her readings of the viewpoints of the participants. The researcher's previous work in education with Gypsy, Roma and Traveller families, and academic work in Romani Studies, provided a sound basis for undertaking the present study, giving her both practical and theoretical experience. This was invaluable in contextualising the study, in contacting appropriate gatekeeping organisations, and in providing a sense of being comfortable, on the part of the researcher, when talking to the

Roma participants. The researcher hoped that this would also contribute to the participants feeling comfortable themselves. Nevertheless, it was impossible for the researcher to approach the present study without bringing preconceived ideas to its design and development. The researcher was a white British, middle class academic person in her sixties, interviewing Roma participants with whom she did not have a personal relationship. Inevitably, the participants responded in their own ways to however they perceived the researcher, just as she responded to each of them. The presence of interpreters and representatives also influenced the style and direction of the interviews. However, the present study takes its theoretical cues from post-structuralist thinking, and an understanding of the influence of differing discourses and ideologies on beliefs and behaviour is central to the interpretations made by the researcher. Discourses and narratives influencing her own position were seen as an integral aspect of the study. The interview process was seen as a joint work between the researcher and the participant, with both contributing to the direction and development of the interview conversation. (For reflexive observations see Appendix A.)

Table 1: The interviews

Participant number	Participant nationality	Language used for interview	Interpreter required?	Representative present?	Length of interview
1	Polish	English	No	Yes	28 minutes
2	Polish	English	No	Yes – Interviewed with participant 3	56 minutes
3	Polish	English	No	Yes – Interviewed with participant 2	2 and 3 = one interview
4	Romanian	English	No	No	27 minutes
5	Polish	English	No	Yes - Sister also present during interview and made some comments	40 minutes
6	Polish – born in Germany	English	No	No	34 minutes
7	Romanian	English	No	Yes	16 minutes
8	Polish	Polish and English	Yes – Polish interpreter	No	46 minutes
9	Polish	Polish	Yes – Polish interpreter	No	33 minutes
10	Polish	English	No	No	38 minutes
11	Polish	Polish	Yes – Polish interpreter	No	31 minutes
12	Romanian	English	No	No	1 hour 25 minutes
13	Bosnian	English	No	No - Interviewed with participant 14	44 minutes
14	Kosovan	English	No	No - Interviewed with participant 13	13 and 14 = one interview
15	Slovak	Polish and English	Yes – Polish interpreter	No	49 minutes
16	Polish	Polish and English	Yes – Polish interpreter	No	39 minutes
17	Polish	English	No	No	40 minutes
18	Romanian	English	No	Yes - Wife also present during interview and made some comments	29 minutes
19	Polish	Polish and English	Yes – Polish interpreter	No	35 minutes

Although the same question schedule was used in each case, the length of the interviews varied considerably. The shortest interview (16 minutes) took place in a coffee shop, where the environment was not ideal, and the participant needed to return to her work nearby. The longest interview (1 hour 25 minutes) was conducted in two parts, as the setting closed for the day before the interview had ended. In general, the length of each interview was determined by the degree to which the participant or participants became involved in talking about the topics discussed. If the researcher felt a participant was becoming tired or restless, she ended the interview without necessarily asking every question. The varying lengths of the interviews reflected the diversity among the participants, and their differing engagement with, and enthusiasm for, the interview topics.

4.4.2 Voluntary work

During the early stages of the project, as part of the process of creating a sampling frame, the researcher undertook voluntary work with a charity working with and for Roma people in northeast London. This took place weekly between June 2016 and February 2017, and consisted of administrative work, supporting a Roma mental health project (22 days), including attending Roma peer support meetings regarding aspects of health and well-being (2); the charity's AGM (1); the Roma Refugee and Migrant Forum (1); and the Roma Bridging Sounds Orchestra at the Music for Youth Proms, Royal Albert Hall (1). The researcher kept notes, recording her observations whilst undertaking duties as a volunteer, and tried to reflexively interpret her experiences.

The researcher was able to hear current conversations between and concerning Roma people in the UK, and to consider the discourses through which they, and others, are constructing and understanding their experiences. These included, but were not limited to, health and well-being experiences, particularly with regard to mental health. This direct engagement offered rich opportunities for gaining insight into the study area and supported the credibility and trustworthiness of the interpretation of the data from the in-depth individual interviews. This opportunity widened the researcher's existing experiences and understandings regarding the lives of Roma people, much of which had been gained through work in the field of education.

4.5 Qualitative research data analysis

A critical, thematic analysis method was used to analyse the data from the interviews (The University of Auckland, 2018). This method was chosen as it offered a clearly defined set of procedures with which to approach the data within the study's post-structuralist framework (ibid.). Unlike a discourse analysis, the present study recognised the importance of the constitutive nature of language and discourse but did not seek to undertake a micro-analysis of the way language was used by the participants (ibid.). Critical thematic analysis can be used to analyse most forms of qualitative data, thereby addressing the questions posed by a constructionist or post-structuralist approach (ibid.). Ritchie et al. (2014: 270) note that analysis ‘requires a mix of creativity and systematic searching’ and that the process of ‘forming ideas to pursue, phenomena to capture and theories to test’ continues throughout the whole process of a qualitative research study. At the same time, they note the importance of transparency when describing the ways in which data has been analysed. They note two key processes that make up the totality of thematic analysis, firstly, data management and, secondly, abstraction and interpretation (ibid). Each of these processes is discussed in the following sections.

Thematic analysis allowed the researcher to look for themes or patterns across the data set as a whole (ibid.). From a post-structuralist perspective, themes involving opinions, ideas or beliefs arise from meanings carried within discourses, narratives or ideologies. Themes of a material nature are understood as being influenced by behaviours and actions arising from meanings transmitted through discourses, narratives or ideologies (Howarth, 2013). An analysis of key themes in a data set can show how discourses are operating within a field of interest, which actors are influenced by which discourses, and where different discourse or ideology has led to conflicting views or outcomes. From such an analysis, it may be possible to identify areas where difficulties could be addressed, based on an understanding of the meanings contained within differing views. In the case of the present study, this required a consideration of the range of discourses regarding Roma health and well-being that exist within the EU, academia, the NHS and the voluntary sector, as well as discourses within Roma communities themselves, and discourses influencing the researcher. A further aspect of the analysis involved considering governmental and societal structures impacting on Roma health and well-being, the contingent and unstable nature of these structures and the resulting possibilities for resistance on the part of Roma people (ibid.). When analysing the data from the individual interviews, the researcher was interested in Roma identity and agency in relation to health and well-being. Issues relating to culture were also seen to be central to existing narratives about Roma health and well-being, and about Roma people more widely, as were ideas relating to nomadism and marginalisation. At the heart of the present study was the researcher’s wish for the voices and views of the Roma participants to be its central focus. The use of critical thematic analysis enabled patterns within the data to be reflexively analysed using the concepts of voice, culture, identity, agency and nomadism from a post-structuralist perspective.

4.5.1 Understanding thematic analysis

Braun and Clarke (2006) suggest that thematic analysis offers an approach to analysing qualitative data that is accessible and, also, flexible enough to be used with a wide range of theoretical approaches. They argue (ibid: 2006: 4) that thematic analysis 'should be considered a method in its own right'. Braun and Clarke (ibid.) suggest that thematic analysis is an analytic method that is independent of a particular theory or epistemology, unlike the analytic methods attached to, for example, conversation analysis, interpretative phenomenological analysis, grounded theory, discourse analysis or narrative analysis. However, although thematic analysis has no identified theory backing it up, theoretical assumptions will always lie behind its use, whether or not these are consciously acknowledged. Within the recognised flexibility of thematic analysis, Braun and Clarke (ibid.) aim to offer clear and concise guidelines regarding its use. In particular, this allows thematic analysis to be undertaken in a way that is compatible with the theoretical and epistemological approach of an individual research study. They stress the importance of linking the analytic method chosen to the epistemological assumptions of a particular study.

In introducing their approach, Braun and Clarke (ibid: 6) state that '[t]hematic analysis is a method for identifying, analysing and reporting patterns (themes) within data'. They emphasise the active role played by the researcher in identifying patterns or themes, and refute the idea that themes are 'embedded' in the data and 'emerge' or are 'discovered'. The researcher must acknowledge the theoretical framework within which the analysis is taking place, as well as the decisions that they take regarding their interpretation and understanding of the data (ibid.). In the case of the present study's post-structuralist epistemology, patterns were understood to be culturally produced. The analysis was undertaken with the twin aims of understanding the constructions made by the Roma participants of their experiences of health and well-being in London, and the ways in which those experiences are influenced by the constructions made of the Roma by others. Language is seen here as constitutive of social meaning (Belsey, 2002) but the language used is not itself analysed.

Themes or patterns were searched for across the entire data set, using a deductive approach (Braun and Clarke, 2006), initially identifying topics of concern to the Roma participants themselves. This process of determining key themes within the data was later followed by an exploration of these themes in relation to a post-structuralist understanding of the position of the Roma in modern Europe and the implications of this positioning for their health and well-being. This further stage of the analysis was driven by the researcher's theoretical interest in the culturally constructed nature of knowledge and the implications of these cultural discourses on the area under consideration, namely the health and well-being experiences of migrant Roma people living in London at the time of the fieldwork. This process was comprehensive and informed the eventual discussion of the findings of the analysis.

Braun and Clarke (ibid: 14) argue that 'thematic analysis can be conducted within both realist/essentialist and constructionist paradigms, although the outcome and focus will be different from each'. They note that, from a constructionist perspective, the relationship between motivations, experience and meaning is not straightforward, as might be assumed with a realist/essentialist approach. Referencing Burr (1995), Braun and Clarke (ibid: 14) state: 'In contrast, from a constructionist perspective, meaning and experience are socially produced and reproduced, rather than inhering within individuals'. They note that thematic analysis focusing on latent themes will tend to take a more constructionist approach, although this is not always the case. The present study took up a position based on the post-structuralist epistemology discussed in Chapter three.

Braun and Clarke (ibid.) conclude their discussion of the ways in which thematic analysis may be used by considering the significance of questions within a research project. As well as an overall research question and, possibly, narrower research questions, which may change as the project develops, there may also be questions that participants respond to in interviews and focus groups. There are also questions guiding the coding and analysis of the data. They suggest that there need not be, necessarily, a relationship between the various questions employed throughout the study. On the contrary, they see a disjuncture between the different levels of question as an aid to a genuine analysis of the data, through the opening up of new ideas and further questions.

4.5.2 Practical stages of thematic analysis

The researcher followed the guidelines suggested by Braun and Clarke (ibid.), regarding the practical stages of using thematic analysis.

1. Familiarising yourself with your data

This stage involved immersion in the data, through the process of producing written transcriptions of the verbal data, reading and re-reading the transcriptions, listening to the tape recordings for accuracy and making initial notes, before beginning the coding process.

The process of analysing the data from the interviews began with the transcription of the conversations from the tapes. A transcriber was employed, due to the time-consuming nature of the task. Issues arising during transcription were discussed with the transcriber from the beginning of the transcription process. These discussions included wider issues with regard to the politics of transcription (Bucholtz, 1999).

The politics of the interpretation and representation of spoken discourse are extremely complex, and the bias of the transcriber inevitably influences the nature of a transcription (Oliver et al., 2005; Bucholtz, 1999). As Bucholtz (ibid: 1463) notes, in the conclusion of her fascinating examination of the impossibility of representing speech in written form:

> The transcription of a text always involves the inscription of a context. The conditions of the transcribing act are often visible in the text: the transcriber's goals; her or his theories and beliefs about the speakers; her or his level of attention to the task and familiarity with the language or register of the discourse; and so on. And this context is social and political in nature: the transcription practices of individual transcribers emerge in large part from the practices of the surrounding community, whether this is a transcribing service employed by a police department, a newsroom, or an academic discipline. Because transcription is an act of interpretation and representation, it is also an act of power. As Mishler (1991: 227) points out, 'there is no way not to make such decisions'.

Bucholtz's position (ibid.) echoes the understandings of post-structuralist theory and offered a theoretically appropriate starting point for the analysis of the data. The transcriber, who was known to the present researcher, was employed to transcribe the recordings of each of the semi-structured individual interviews. At the beginning of, and during, the transcription process, these issues were discussed with the transcriber, an experienced interpreter and translator, including the difficulties involved in representing the spoken discourse of second and third language speakers. In order to sustain awareness of the bias involved in working with the empirical data, the researcher and transcriber engaged in an ongoing conversation about this process. Following discussion, thoughtful transcripts were produced, which provided a sound basis for the analysis to begin.

On receipt of the transcripts, the researcher listened to the recordings again, checking her hearing of the conversations against that of the transcriber. Initial ideas were noted, in preparation for starting to generate initial codes. A small number of alterations were made to the transcripts, based on the researcher's hearing of the conversations and her memory of the interviews. In a few places, words were heard completely differently by the transcriber and by the researcher and it is interesting to note that such differences could, potentially, alter the sense of a response, sometimes significantly. It was also noted that the use of the transcriber, as someone removed from the interview context, enabled the voice of the researcher to be treated in a similar way to those of the other participants, something less likely to happen if the researcher was also the transcriber. In analysing the content of the interviews, the researcher referred constantly to both the recordings and the written transcriptions, to try to ensure a degree of reflexivity, as the work progressed.

2. Generating initial codes

The second stage involved coding interesting features of the data across the entire data set. The University of Auckland (2018: 1) identifies the difference between a code and a theme, noting that '[a] theme captures a common, recurring pattern across a dataset, clustered around a central organising concept. A theme tends to describe the different facets of that singular idea, demonstrating the theme's patterning in the dataset.' Codes are conceptualized as the building-blocks that are combined to create themes: 'Codes tend to be more specific than themes. They capture a single idea associated with a segment of data and consist of pithy labels identifying what is of interest in the data (in relation to the research question)' (ibid: 1).

Key features of the data set that suggested significant ideas in relation to potential themes were recorded, with their relationship to the post-structuralist framework of the study being noted. Individual transcripts were then systematically worked through and annotated with these ideas in mind. Additional potentially significant codes identified in individual transcripts were also noted. Key aspects of the speech within the interviews as they related to the identified codes were highlighted on the transcripts. A table was created for each interview, recording speech relating to each identified code and its location within the transcript. The coding process throughout was data-driven since, whilst the existing literature suggested a range of possible themes, the intention of the present study was to examine the data in depth, and to avoid any pre-determined assumptions as to what its participants might report.

3. Searching for themes

At this stage, codes were collated into potential themes and sub-themes. A table was created for each potential theme, with sub-themes, where codes, relevant speech and the location of these within each transcript, were recorded as they related to the potential themes. Once the potential themes were established, an initial thematic map was created.

4. Reviewing themes

Stage 4 involved reviewing and refining the themes. Themes that were insubstantial were discarded, some were collapsed together to form a single theme, and others were broken down to create separate themes. Braun and Clarke (2006: 20) note that 'Patton's (1990) dual criteria for judging categories – *internal homogeneity* and *external heterogeneity*- are worth considering here. Data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes' (original italics).

The first phase of this review involved ensuring that the coded data extracts for each theme formed a coherent pattern. Following the second phase, in which the coded data was reviewed against the entire data set, a more refined thematic map was created. At this point, the researcher began to consider the overall story told by the themes about the data, within the post-structuralist theoretical framework of the study.

5. Defining and naming themes

The identified themes were then defined and further refined to capture the essence of each theme, together with the relationships between the themes overall. The collated data extracts for each theme were revisited and organised into a coherent and internally consistent account, and a final thematic map was constructed with each theme being clearly and concisely named. The narrative to accompany the identified thematic map was then drafted.

6. Producing the report

When writing about the analysis, to retain the vibrancy of the conversations, all participants were given pseudonyms, as were interpreters and representatives present during the interviews. In stage 6, the story told by the data about the health and well-being of Roma people in London was written up (Chapter five). Data extracts were chosen to illustrate the themes within the data, to capture the essence of the points being made. In the discussion (Chapter six), the findings were embedded within an analytic narrative, *using the concepts of voice, culture, identity, agency and nomadism to connect the story within the data to culturally constructed discourses impacting on Roma health and well-being*. The implications of these discourses on Roma health and well-being experiences in London were considered within the narrative.

4.6 Ethical issues

4.6.1 Information for organisations

Information about the present study was provided for all organisations approached during the recruitment process. This document outlined the scope and purpose of the research, as well as the process for obtaining participant consent and arrangements for protecting confidentiality. Contact details for the researcher and for the first supervisor were provided. The information for organisations was given to both the individuals providing contact with research participants on the ground, and to the managers of the organisations for which they worked.

4.6.2 Participant consent process

The information for participants and the participant consent form were made available in English but were also translated into Polish and Romanian, which were the languages of the countries of origin of most participants. All participants were given time at the start of the interview to read in an appropriate language, or to have read to them, the information for participants, which outlined the purpose of the research and arrangements for protecting confidentiality. Participants were told that the interviews would be tape-recorded and reassured that the information they provided would be anonymised and would be stored safely. Contact details for the researcher and the first supervisor were included in this information, along with an option to opt out, if the participant should change their mind following the interview. After reading this document, which participants retained, they were invited to read, or have read to them, and sign, the participant consent form. Everyone who reached this stage proceeded with the interview and no-one opted out afterwards. Copies of the consent form, signed by each participant, were retained by the researcher.

4.6.3 Initial steps taken to address ethical concerns

In July 2016, an application for ethical approval for the present study was submitted to the University Research Ethics Committee (UREC). Along with general considerations regarding all research involving human subjects, the researcher was aware that research undertaken with members of marginalised groups, including Roma people, required additional thought. The following questions were required to be addressed within the application for ethical approval: What do you consider are the main ethical issues and risks that may arise in this research? What steps will be taken to address each issue?

A number of potentially ethically problematic issues were foreseen:

The focus of the study on Roma community members only;
Issues regarding the personal nature of health and well-being experiences and possible cultural prohibitions on discussing these;
Participants as members of minority ethnic groups, deemed vulnerable under data protection legislation;
The possibility of hostility towards an academic study undertaken by a non-Romani researcher;
Possible bias on the part of the researcher, as well as that of translators and interpreters;
The safety of a researcher working alone;
Issues regarding confidentiality and the secure storage and disposal of the data.

The application for ethical approval echoed the background information and the findings of the literature review, in positioning the Roma as vulnerable, in this case as members of a minority ethnic group. Ideas about cultural prohibitions when discussing aspects of health and well-being, and about in-group participants and an out-group researcher, reflected some of the ways in which Roma people represent themselves and are represented by others. The choice, itself, of Roma people as subjects of the present study, rather than people from other groups, spoke of a positioning of the Roma as culturally different, vulnerable and marginalised.

The term “Roma” used at the Council of Europe refers to Roma, Sinti, Kale and related groups in Europe, including Travellers and the Eastern groups (Dom and Lom), and covers the wide diversity of the groups concerned, including persons who identify themselves as Gypsies’ (Brown et al., 2013). The focus of the present study was on Roma community members who had migrated from CEE countries, rather than on the whole Romani and Traveller collectivity. The researcher was interested, specifically, in the impact on health and well-being of Roma migration in the context of European intervention in Roma people’s lives. The justification for the focus of the research was explained to participants at the time of recruitment and, despite contestation within the communities (National Roma Network Forum, Birmingham, 29th September 2015) around the definition of ‘Roma’, no-one who was involved in the recruitment process, or who was interviewed, questioned the focus of the study.

The subject matter of the present study related to issues of health and well-being, which tend to be of a personal nature. It was anticipated that participants might find talking about these matters difficult, particularly with a researcher who was not a member of their community. The researcher felt that the strong boundary between all Romani groups and outsiders could lead to mistrust or discomfort, and that cultural factors might influence what participants felt able to discuss. The researcher had many years' previous experience in working with members of the Roma communities within the education sector, as well as previous academic experience in this area, and this background enabled the fieldwork to be approached with sensitivity to Roma culture. During the interviews, it was made clear to participants that they were under no pressure to discuss any matter they did not wish to share, and the researcher managed the timing and pace of each interview according to the response of each participant.

Participants were members of communities that have been subject to discrimination and prejudice over many centuries. Although, at the time of the interviews, all were likely to have the right to live in the UK under EU legislation, or as former asylum seekers, in a broader social and political sense, the representation and positioning of Roma people is tenuous and subject to wide debate. In recent years, there has been a growth in the number of interventions, both practical and academic, made by non-Romani organisations and individuals in matters concerning Romani communities. Although these all profess to be in the interests of Romani communities, there is an increasing reaction to the power differential at play here, particularly on the part of some Roma individuals and groups. Consequently, it is possible that the study may draw hostility in some quarters.

Given this history, and the uncertainty surrounding UK membership of the EU at the time, it was thought that participants might be wary of formal research projects and would need reassurance from people familiar to them that participation in the research was not unsafe. The fact that participants were recruited through professional organisations working directly with members of Roma communities in London, and that the researcher was already known to the members of staff who facilitated introductions, helped to mitigate against this potential difficulty. In addition, several participants chose to have representatives from these organisations with them, whilst the interview was conducted. The use of interpreters who were known to the participants, where required, also contributed to a secure environment for the participants. The researcher introduced herself and briefly described her previous work with members of the Roma communities. The reasons for undertaking this research were explained along with potential benefits to community members across the UK, through the anticipated guidelines for healthcare professionals. Participants were made aware that regular supervision was provided for the researcher by a team of experienced supervisors. Only one potential participant declined to take part, as they thought that research by non-Roma researchers was frequent but ineffective.

All participants were members of minority ethnic groups, deemed vulnerable under data protection legislation, and could, potentially, belong to other vulnerable groups, including elderly people, physically or mentally ill people, people with learning difficulties or bereaved people. Every effort was taken, at all stages of the study, to ensure minimal risk of harm to participants, including emotional and mental distress, and any possible damage to social standing. No participant became distressed during the interviews but, following one interview, the researcher gave information about a local food bank to the participant, and another was advised to seek help regarding a hospital appointment from the mental health project of the charity.

Questions regarding the security of personal data, and the retention and disposal of the data, were clarified for all participants at the start of each interview. This information was provided within the 'Information for Participants' leaflet, available in English, Polish and Romanian, which participants retained following the interview, and participants were advised at the time of recruitment that all personal data collected, including the transcriptions of interviews, would be made anonymous. Through the information leaflets and the recruitment process, participants were advised that electronic data would be password protected. They were informed that the University of Greenwich stores research information securely for five years and that the outcomes of the study would be presented in written form as a post-graduate research thesis.

Minor amendments to the study methods were requested by the University Research Ethics Committee, including the addition of a unique number for each participant, thus enabling anonymity, and a widened list of options for participants to confirm their understanding of the process, and approval was subsequently granted (See Appendix D). During the course of the study, the steps taken to address ethical issues appeared to be effective. In the cases of two participants, other family members were present whilst they were being interviewed, and both contributed views to the conversation. One family member was under the age of eighteen but, in both cases, the material used was purely that contributed by the participants themselves.

4.6.4 Further ethical considerations

Ritchie et al. (2014) note a broad consensus regarding key principles relating to research ethics. These include the need for informed consent and voluntary participation; respect for confidentiality and anonymity; avoidance of adverse consequences of participation and awareness of risks of harm; and the need for research to be worthwhile and to not place unreasonable demands on participants (ibid.). At the same time, they point out that ethics codes are generally developed for a predictable quantitative biomedical model, and do not take account of the dynamic, unpredictable and iterative nature of qualitative research. They suggest that, consequently, codes and guidelines alone are insufficient. In addition, debate remains about ethical approaches to research, particularly regarding different ontological views and situational responses to emergent and contextual issues (ibid.).

Research framed within post-structuralist thinking understands all ontological positions as historically and culturally contingent, and knowledge construction to be the domain of contingent narrative and discourse. The present study, therefore, which questions any notion of meaning as foundational, required a high degree of reflexivity on the part of the researcher. It was necessary to reflexively consider power dynamics and influences affecting changes made to the study design, the role of the transcriber, recruitment of participants and engagement with gatekeepers, the position of the university and the researcher, and working with vulnerable subjects.

Changes were made to the study design for the reasons outlined above, resulting in outputs that were different from those originally proposed, and in changes to the information initially presented to the participants. Ritchie et al. (ibid: 78) suggest that a thoughtful and reflective approach to qualitative research '…means developing an ethical conscience that puts participants' interests at the heart of decision-making'. The decision to make these changes was taken by the researcher, together with her supervisors, but was led by the findings from the individual interviews with the participants. Although this decision was based on the voices of the participants and the views that they expressed, however, they were not directly part of this process. Ideally, perhaps, all the participants might have been consulted. However, recruitment of the participants had been difficult and, together with their own lack of desire to take part in ongoing aspects of the study, revisiting each individual with an interpreter would have been extremely difficult, if not impossible. It would also be unlikely that all participants would agree on the best outputs for the study, thus raising further issues regarding the fair representation of their views. Nevertheless, it remains true that the power to make these changes lay with the researcher and supervisors, rather than with the Roma participants.

The politics of transcription were discussed in section 4.5.2 (Bucholtz, 1999), in relation to the data analysis process, along with actions taken to mitigate issues regarding the interpretation of the interview recordings. In section 4.3.5, the complex mediating effects of interpreting and translation on the present study were considered. The transcriber had lived for a long time in another western European country. She, therefore, shared with the study participants an experience of migrating, and of seeking healthcare in a language that was not her first, although with the benefits of higher education and secure housing that not all the study participants enjoyed. The transcriber had also previously worked with Roma pupils in a school in her new country, using her second language and their third. The researcher and the transcriber had known each other for many years and had talked about their respective work. Whilst this might be seen as something that could prevent a detached, professional relationship, it actually provided the opportunity for fruitful discussion about the transcription process. These circumstances enabled the transcriber to approach producing the transcriptions with understanding, in relation to the experiences of migrant Roma people in western Europe.

Practical issues regarding the recruitment of participants for the present study are discussed above, along with the use of gatekeepers as a way of generating a sampling frame (Ritchie et al., 2014). At the time of the interviews, the number of London organisations working directly with Roma people was very limited, resulting in a small pool of accessible participants, and the present researcher's previous work experience and contacts offered solutions to this practical difficulty. At the same time, Ritchie at al. (ibid.) point out the possibility of bias in relation to the individuals chosen by gatekeeping organisations. This echoes the discussion by Goulet and Walshok (1971), which suggested that more marginalised members of communities might not be included in research, leading to bias within study samples. In this situation, a degree of power lay with the gatekeepers, both in relation to the researcher and to potential participants, who may have felt obliged to take part due to their dependence for support on the gatekeeping organisations (Ritchie et al., 2014).

Bhopal and Myers (2008) suggest that the position of the gatekeeper is both powerful and weak. Gatekeepers block or allow access to potential research communities, and their decisions impact both these communities and researchers, who may be denied access to potential participants. They state (ibid: 47): ‘The gatekeeper is not only endowed with ‘expertise’ about the community, therefore: he or she is also in a powerful position regarding the exercise of interaction between the Gypsy and non-Gypsy community.’ This route to access is also not the experience of many other research subjects, who may be contacted more directly. However, the power of gatekeepers to Romani communities sits alongside a weaker position in relation to the low priority allocated to funding and resources for the communities with which they work, of which they may or may not be members (ibid.).

Despite this reliance on gatekeepers, there was diversity within the sample group of the present study, in terms of age, country of origin and level of education. However, in the case of gender, more women than men took part. This bias towards women was also reflected among the gatekeepers, all of whom were women, who may have had closer relationships themselves with their female clients, or more of their clients may have been women due to the nature of the support offered by the gatekeeping organisations. The researcher was a woman, three of the four interpreters and one representative were women, and the transcriber was a woman. The men who took part had strong voices, but it may be that a bias towards women as participants led to aspects of men’s experience being missed.

Additionally, Bhopal and Myers (ibid.) consider the position of the Academy or University and the positioning of the researcher. They refer to questions about the ownership of meanings and understandings produced through research, and the importance of acknowledging power relations between various parties involved in the research process, as well as the impact that power differentials might have on the findings. Noting the outsider role of the researcher and the researcher’s highly positioned voice, Bhopal and Myers consider the researcher’s relationship with political discourse about members of Gypsy, Roma and Traveller communities. They propose that scholarly representations of these communities are often compromised, and that too sympathetic a position on the part of the researcher may limit academic understanding. Pointing out that academic research can shape policy affecting the everyday lives of community members, they suggest that: ‘The opening up of an alternative engagement, one that acknowledges the differences between researcher and subject and seeks to create understandings within that dialogue, may be more fruitful to all parties concerned' (ibid: 58). The present researcher's reflexive thinking about these issues is developed in Appendix A.

The notion that Roma research subjects are 'hard to reach', and require mediation through gatekeepers, is closely linked to the concept of vulnerability. Data protection legislation (Data Protection Act, 2018) positions a wide range of research subjects as vulnerable and provides guidance for researchers and research organisations. Members of minority ethnic communities, along with members of other groups, are deemed to be vulnerable and to require researchers to consider additional ethical issues or concerns (Economic and Social Research Council, 2023). In the context of a particular research project, potential negative consequences due to participation should be assessed, with efforts made to ensure freely given informed consent (ibid.).

Gordon (2020) notes the centrality of the concept of vulnerability, and the minimisation of risk, to ethics in human subjects research, but distinguishes between a categorical and a contextual approach. Gordon (ibid.) suggests that the categorical approach, or designating members of certain groups as vulnerable, fails to account for multiple vulnerabilities, variation in the degree of vulnerability experienced by group members, or situations in which research subjects may be considered vulnerable. A contextual approach therefore offers a more nuanced understanding of the nature of vulnerability, and vulnerability as occurring along a spectrum of seriousness. This allows a more focused and appropriate approach to be taken towards safeguarding the interests of research participants (ibid.).

Alongside this, Ritchie et al. (2014) draw attention to the protective or defensive nature of research ethics discourse, and contrast this with the right of people to participate in research and express their views. They compare protection of participants with their agency and note the need to ensure the inclusion of diverse perspectives. In the case of the present study, a strong focus on the voices of its participants offered an opportunity for participants' agency within the research process. Together with facilitating the right of people to be heard is the responsibility for ensuring that research data are reported with integrity (ibid.). The present study gives considerable space to direct quotes from the transcribed data, facilitating individual participants' right within qualitative research to be heard. The provision of translators and interpreters, as well as representatives present during interviews where requested, also served to protect participants who otherwise would have been excluded. All the provisions described were put in place with the aim of keeping participants' needs at the centre of decisions throughout the duration of the study.

A more direct critique of notions of vulnerability is offered by Butler (2020) who, whilst acknowledging basic human requirements for food and shelter, strongly questions the creation of a class of people who identify primarily with the category of vulnerability. She suggests (ibid: 2) that it can neither be isolated from other terms, nor used as a foundational aspect of political thinking: 'Is anyone vulnerable, for instance, without persisting in a vulnerable condition?'. Butler also asks how we should understand those who, while living in a condition of vulnerability, seek to resist that very condition, thus changing vulnerability from a passive to an active experience.

Butler (ibid: 5) identifies the paternalistic character of notions of 'protection' of vulnerable populations, suggesting that: 'Relief from precarity is good, but does that approach grasp and oppose the structural forms of violence and the economics that dispose populations to unlivable precarity?'. For Butler (ibid: 11), vulnerability can be understood as a feature of social relations, rather than as an identity or category, or even a ground for political action:

> Rather, persistence in a condition of vulnerability proves to be its own kind of strength, distinguished from one that champions strength as the achievement of invulnerability. That condition of mastery replicates the forms of domination to be opposed, devaluing those forms of susceptibility and contagion that yield solidarity and transformational alliances.

Ethical requirements to place the needs of the participants at the heart of decision making did not preclude critical thinking about the category of vulnerability in relation to all Roma people in all circumstances.

4.7 Overview of methodology and methods

In Chapter four, the methodology and methods used to carry out the present contextual and explanatory study were outlined and discussed. This study drew its methodology from the qualitative research approach used, and the nature and purpose of qualitative research, along with ontological and epistemological understandings of qualitative research in general, were considered. Referring back to Chapter three, points of ontological and epistemological divergence and agreement between qualitative research more widely and post-structuralist thinking were noted. The suitability of a qualitative research approach as related to post-structuralism was discussed. The second part of this chapter described the study design, including the type of study devised, changes made to this design and their implications, setting, sampling and recruitment. The significance of interpreting and translating within the present study was considered, and the method of data collection, through in-depth individual interviews, and data analysis using a critical, thematic analysis method, was discussed. Potential ethical issues and the ways in which these were addressed were also noted. In Chapter five, the findings from the analysis of the individual interview data are presented.

FINDINGS

5.1 Introduction

Chapter five presents the findings from the individual interviews and relates these to the literature. Footnotes refer to understandings gained from the voluntary work undertaken by the present researcher, as well as attendance at conferences. Chapter five also points to the ways in which the discussion, in Chapter six, picks up the connections between the literature and the findings of the present study, and problematises these through the concepts of voice, culture, identity, agency and nomadism, from a post-structuralist perspective. The concepts lead to a critique of traditional perceptions of Roma representation and Roma health and well-being and contribute to themes emerging within the more recent literature examined (Grill, 2012, 2017; McFadden et al., 2018a; Morell et al., 2018; Nagy, 2018; Smith, 2018; Bobakova, 2019; Kühlbrandt, 2019; Orton et al., 2019; Petraki, 2020; Cohen, 2021; Kapadia et al., 2022). This critique focuses on Roma self-representation, agency, identification with the experiences of members of other communities and a recognition of change within Roma culture. Nevertheless, ongoing oppression, exclusion, silence in relation to the needs of Roma people and poor distribution of healthcare resources in CEE countries remain critical.

The practical stages of conducting a thematic analysis, outlined in Chapter four, were followed (Braun and Clarke, 2006). The study participants, as well as representatives and interpreters, were given pseudonyms to protect their anonymity. The present study concentrates on longer-term residents in northeast London, finding adaptation and change together with continuing difficulties. Twelve participants were Polish, four were Romanian, one was Bosnian, one Kosovan and one Slovak. It is acknowledged that a more diverse cohort, including recent migrants, might have reported different experiences and that the generalisability of the present study's findings is, consequently, limited. Adding to the information given in Chapter four, Table 2 offers a brief introduction to the participants. Some personal details, disclosed by the participants, have been omitted to preserve confidentiality.

Table 2: The Roma participants

Participant number	Participant pseudonym	Participant nationality	Participant age at time of interview	Length of time in UK at time of interview
1	Magdalina	Polish	33	Arrived 2001, as asylum seeker
2	Sabrina	Polish	23	7 years in UK Also, in UK as a child
3	Paulo	Polish	27	7 years in UK
4	Lavinia	Romanian	40	6 years in UK
5	Artur	Polish	19	17 years in UK
6	Pansela	Polish – born in Germany	20	17 years in UK
7	Mirabella	Romanian	26	11 years in UK
8	Agata	Polish	45	20 years in UK
9	Daniella	Polish	65	18 years in UK. Arrived as asylum seeker
10	Samuel	Polish	33	In UK 2008 – 2011. In Poland 2011 – 2015. Returned to UK in 2015
11	Agnieska	Polish	Not stated	Permanent residence. Arrived as asylum seeker
12	Nicolae	Romanian	29	Arrived in UK July 2012
13	Margaryta	Bosnian	37	20 years in UK. British citizen
14	Elise	Kosovan	40	11 years in UK. Kosovan citizen
15	Dana	Slovak	46	In UK since 2006. Has residency permit
16	Debora	Polish	Not stated	14 years in UK. Has the old residency permit. Needs to apply for new permit
17	Florin	Polish	33	18 years in UK. Recently obtained British citizenship
18	Marcin	Romanian	Not stated	Asylum seeker 1998. British citizen 2006
19	Kristina	Polish	Not stated	Seeking right to remain in UK, for herself and mother

5.2 Overview of findings

The focus of Chapter five is on the voices and views of the Roma participants, on the stories and experiences that they chose to speak about in relation to health and well-being, and the ways in which they spoke about these. The interview schedule covered the following topics: general use of healthcare and well-being services, in the UK and in countries of origin; barriers and the impact of migration; specific aspects of healthcare and well-being services, including maternity and children's services, care of the elderly, Roma healthcare in previous generations, mental health and well-being, smoking and childhood hearing impairment; and further points for discussion and clarification. In relation to these topics, participants described a wide range of experiences: their own, those of relatives and friends, and those of members of the Roma communities more widely. They seemed to want to talk about their experiences of health and well-being in London, and often related these to their experiences in their countries of origin.

The open-ended topics within the semi-structured interview schedule allowed the participants space to respond with personal stories about their experiences. In some cases, the stories they told were long and detailed, suggesting a need for these experiences to be heard. The interview schedule formed the basic structure of the interviews, with the researcher following the directions taken by the participants within each topic and asking further questions to develop the conversations. As discussed in Chapter four, the focus on voice within the present study is significantly mediated by issues of translation and interpretation.

The stories recounted by the participants were located within their experiences of migration to the UK. Behind these individual migratory journeys lay the broader history of the Romani diaspora, a relatively recent nomadic lifestyle, and centuries of persecution, described in Chapter one. Regarding health and well-being services in London, participants identified several areas contributing to serious accessibility difficulties, as well as factors that served to facilitate improvements in the health and well-being of themselves and of others in the Roma communities. Positive, as well as much more difficult, experiences were reported. Running through the participants' stories was a strong thread regarding the impact of change on Roma people's health and well-being, and factors impacting particularly on the different generations.

Whilst individual responses were varied, and there was disagreement amongst participants about different aspects of their experiences, there was also considerable synergy across the participant cohort regarding the views expressed. For example, sixteen participants identified communication difficulties as a major barrier to accessing services and treatment, and eight participants described issues relating to low levels of education as presenting barriers. Barriers arising from cultural factors were noted by twelve participants, with ten participants identifying a direct causal link between cultural factors and poor health and well-being. Alongside this, seven participants noted Roma cultural taboos inhibiting the recognition and treatment of mental health conditions. Whilst sixteen participants reported negative health and well-being experiences in London, with eight describing experiences of prejudice and discrimination, eighteen participants reported positive experiences. Twelve participants spoke of the impact of wider societal change on Roma health and well-being. Whilst these changes were largely seen as unhelpful, some were believed to be beneficial. Issues affecting young Roma people in London were noted by five participants and fourteen spoke of those affecting older Roma people. In each case, both positive and negative aspects were noted. Among factors enabling improved health and well-being, the importance of education and rights was emphasised by eleven participants, and eleven participants stressed the need for a preventative approach.

This broad analysis enabled nineteen sub-themes themes to be identified within the data corpus as a whole (Braun and Clarke, 2006). The sub-themes were then organised under five overarching thematic headings: factors contributing to poor health and well-being; barriers to accessing services and treatment**;** experiences of health and well-being services; impact of change, and generational issues; and factors enabling improved health and well-being.

Overlap occurred within and between these themes, as the key points made by the participants worked across the whole picture. This study does not examine a process that has a structure in time, other than the much wider historical story of persecution and migration in which the lives of Roma people in London sit. The findings cannot, therefore, be arranged as stages of a linear or narrative account (Ritchie et al., 2014). Consequently, aspects of each theme are picked up in relation to those of other themes, where this is important to understanding the overall picture.

5.3 Analysis of themes and sub-themes

In section 5.3, each theme with its sub-themes is examined in detail and pertinent quotations from the individual interview transcripts are used as evidence to illustrate, illuminate and expand upon the analysis of the data. (Ritchie et al., 2014). The nuances of the quotations show the richness of the interview conversations (Mason, 2017). However, this focus on the voice is framed within the theoretical understandings of the present study, which recognise the socio-historical context in which individual participants speak (Passerini, 2017; Belsey, 2002), and the effect of the researcher and the research process on the account created from the data (Back, 2017; Passerini, 2017; Barthes, 2010). Tables 3 to 7 show each theme with sub-themes and key corresponding codes. These codes were drawn from the more detailed coding noted during the initial analysis of the interview transcripts of the data collected.

Table 3: Theme 1 – Factors contributing to poor health and well-being

Theme 1	Sub-themes and codes
Factors contributing to poor health and well-being	**Material difficulties** Poverty, money problems, housing problems, poor diet, hunger, smoking **Emotional difficulties** Stress, depression, loneliness, feeling unable to cope, lack of self-confidence, belief that medication can cause addiction, smoking **Physical problems** Chronic health issues, lack of exercise, obesity and overweight, belief that Roma people were healthier in the past, differing views regarding Roma children and hearing loss **Cultural issues** Cultural taboos around health and well-being, including gender, mental health and disability, invisibility of mental health conditions, reliance on faith and church to take care of health and well-being **Broader social factors** Prejudice and discrimination, impact of media representation of Roma people, Brexit, very little dedicated support for Roma people around health and well-being

During the interviews, the participants referred to a range of factors, contributing to the development or maintenance of poor health and well-being amongst members of the Roma communities in London. These were organised into sub-themes: material difficulties, emotional difficulties, physical problems, cultural issues and broader social factors.

Material difficulties

In terms of material difficulties, nine participants spoke particularly of the impact of poverty and money problems, housing problems and poor diet, and one spoke of hunger. These factors were reported by participants of all age groups from Poland and from Romania. Roma people in, or from, all CEE countries were said to be subject to poor living conditions and lack of economic opportunity, which can lead to stress and depression, and this background is then brought with them to London and other parts of the UK. The effect of poverty on physical problems may also pre-exist arrival in London. Nicolae explained the background of Romanian Roma living in London:

> Nicolae: …especially if they're not employed, …then access to the [Romanian] health system is quite reduced. … you can have access to emergency…, health services, but - …for example, if you have an accident, they will operate you for free at the time, but if you have to stay longer in the hospital, then they will invoice you.
>
> Felicity: OK…
>
> Nicolae: …so this creates big problems for people. … if you are afraid that you might suffer [from] something and you want to have a check [in Romania], if you're not employed, then this will cost you a huge amount of money, and people often don't do investigations for years… because they can't afford it.

Speaking about their lives in London, participants described poverty and money worries causing stress, with Pansela suggesting that poverty particularly affected Roma women. Housing was also very problematic for four participants. Individual stories were told about health and well-being issues exacerbated by long periods of time waiting to be rehoused. In one case, a Polish participant's husband was seriously ill with a lung condition and was waiting to move from a second-floor property with no lift. This family had arrived as asylum seekers and had been in the UK for over twelve years. A young Polish husband and wife, who had been in the UK for seven years, spoke at length about the difficulties they faced, following an unwanted move to poor quality private housing in a new borough. Their son had recently been allocated a place at a school catering for his special educational needs. The son had remained at the initial school, but a long bus journey twice daily was affecting the well-being of the whole family:

> Paulo: …you know when she go to school, it's like, four hours, she can't sometimes cook, she have to cook at the night, and she's really tired, you know? For the night, so she needs to go, come back, clean quickly, cooking, it's like depression, it can get - it's, like, stress. So, when I'm stay in the house, I can help. But if I go work, what she can do? For example, I cannot change the school, as I told you before, this arrangement no good…

In addition, they reported that the same son was repeatedly unwell with ear problems because the house was cold, due to a broken heating system and draughty windows remaining unfixed by their landlord.

Four participants also spoke about the negative effect of a poor diet on Roma people's health. It was suggested by Marcin and Samuel that poor hygiene, poor food, and a lack of money for food could all contribute to a shorter lifespan for Roma people. The quality of modern food was also considered important and previous generations were believed to have been healthier. One Roma participant, who worked with members of the Roma communities in London, talked about an event held at his place of work:

> Samuel: - they were more healthy. We just had a talk a few minutes ago with other of our clients, and I think it's not just about Roma people, I think it's all about all people, it's about the food we are eating now, it's junk food, it could be modified, and we just talked that our grandparents they were reaching their eighties, nineties, and now people are dying at the age of fifty, sixty.

However, Samuel believed that aspects of an unhealthy diet were particular to Roma culture, with the change to a sedentary lifestyle being implicated in the development of poor health:

> Samuel: The diet is not very healthy. It's full of meat, and full of fats, and full of carbs and there aren't many veggies or fruits. … I think it's just a specific of Roma culture. In this country or in another country, they eat the same.
>
> Felicity: OK. Why is that, then?
>
> Samuel: I think it's a cultural thing – when they used to be nomadic, obviously it was easier for them to obtain meat – especially when it was cold - than to grow veggies. And I think this is why.
>
> Felicity: Yes, of course, because to grow vegetables you have to settle down.
>
> Samuel: Exactly.

Four participants reported diabetes within the Polish, Romanian and Slovak Roma communities, connected to lifestyle, including modern, processed food. More generally, children were seen to be affected by an inadequate diet. Agata felt that the lack of time now available for all people, including Roma people, to spend with their children led to them being given poor quality 'junk' food, leading to children's ill health and over-activity. However, in some cases, families simply did not have enough to eat:

> Pansela: Well, if I *did* have money I would be going shopping every time, I think I'll feel better, or something, I don't know. But sometimes you know, when we don't have food, especially I'm talking about poor people, they take a cigarette, because they're hungry.
>
> Felicity: Yes, ok…
>
> Pansela: It makes you feel better…
>
> Felicity: Yeah. And does having enough food affect *your* family or… do you have enough food?
>
> Pansela: No, we don't have enough food.

Pansela stressed the importance of the meals provided for her younger siblings at school. When asked if her family used a food bank, she said she had never heard of them.

Participants across the cohort frequently referred to smoking, when discussing negative aspects of Roma people's health and well-being. Smoking, alongside a diet containing too much fatty food, was seen as contributing to an unhealthy lifestyle, and the use of alcohol was also mentioned in this context. Participants spoke of smoking among Roma people as a means of alleviating stress caused by money and housing problems, as well as a way to alleviate hunger, although they expressed differing views when asked if Roma people smoked more than people from other groups. There was, however, a general sense that many Roma adults smoke heavily throughout their lives, and that smoking is very common among Roma people:

> Pansela: Um…yes. There are a lot of smokers. You – there is not even one that you're gonna meet that doesn't smoke.

> Felicity: Right. Do you smoke?
>
> Pansela: Yes. Everyone just smokes.
>
> Felicity: Ok…why do they smoke?
>
> Pansela: Just stress relief.
>
> Felicity: Stress relief, ok. And…what's causing the stress?
>
> Pansela: Mmmm…well, the first time *I* start smoking, it's because…I just had *nothing*. (*pause…)* I was really stressed…when I just took a cigarette while I was crying, I was just thinking what happened - *everything*. *Everything* on my shoulders.

Participants also reported Roma children smoking, sometimes at a young age, and Roma children taking drugs and drinking alcohol.

Overall, a strong picture was painted of lifestyle pressures and material difficulties contributing to both mental health issues and physical problems for people in all Roma communities. The participants' responses reflected the literature, particularly regarding the impact of poverty, poor housing, poor diet and unhealthy lifestyles on the health of Roma people (WHO, 2017; EPHA, 2014; McNulty, 2014; Migration Yorkshire, 2012; Parekh and Rose, 2011; Tobi et al., 2010; TS4SE, 2009). High rates of smoking among Roma people were also reported within the literature (Tobi et al., 2010). Comparisons with the experiences of members of other groups were, however, largely absent and this aspect of the evidence is considered in the discussion, in Chapter six, where the findings of the present study are related to the discussion of the concepts of culture, voice, identity, agency and nomadism.

Emotional difficulties

As well as being an outcome of difficult life circumstances, emotional difficulties, including stress, loneliness, feeling unable to cope and lack of self-confidence, were described by ten participants as contributing to poor health and well-being. Younger and older participants from four countries raised these issues, with triggers including money and housing worries, hunger, illness itself, marginalisation and language barriers. For example, smoking as a response to emotional problems was reported as leading to smoking addiction and smoking-related illnesses:

> Felicity: Why do you smoke?
>
> Artur: I dunno, it's really addictive, I tried to stop it so many times, but it's just really addictive. I think it's cos of this depression. Yeah.

Artur, who had repeated chest infections, feared that giving up smoking after many years might actually worsen his illness. Four participants, who were fully aware of the negative effect of smoking on their health, spoke of the difficulties they had experienced when trying to stop:

> Pansela: Well, I *am* trying to stop. I tried many methods the doctors gave me. But it makes me dizzy, it makes me vomit, I don't think it really helps… it's really, really hard.

Stress, created by the pressures of modern lifestyles, was identified by six participants of all ages and from three countries, as contributing to both physical and emotional problems. These included diabetes among Roma people, and addiction to tablets prescribed for depression, which was said to lead to breathlessness and aggression when the tablets were not taken. Agata, through her interpreter, Elena, described her own experience of overwork leading to a period of breakdown and burnout:

> Elena: Basically, she was working, then she was looking after the house, she was looking after her parents, she was dealing with all the stuff, parent stuff, her stuff, you know? So, she had to – she was like a machine, you know? She had to pull everything; you know? *(Polish)*
>
> And then suddenly she became ill, and she said it would be OK, if there would be, like, one, but it was, like, three, four, and she just couldn't, she just broke down…

Speaking very quietly, Margaryta talked of many people, including Roma people, experiencing a lot of stress caused by illness, bereavement, or the pressures of work and studying, and suddenly developing mental health problems as a result. This scenario included children and young people, and Margaryta spoke of her own anxiety for her teenage daughter, who was studying for GCSE examinations and had been taking caffeine tablets to stay awake, so she could complete her work. Despite Roma children in the UK apparently having fewer concerns than their parents, the pressure of studying was concerning:

> Margaryta: The kids they don't have stress like us before – we… back home, you know, when you're 14, 15, you need to go to the new school, different type they treat you because you're Roma… (*sighs*), you are nothing like the other children, that's pressure. Then, you no going to school…
>
> Felicity: You're saying they would stay away because -
>
> Margaryta: Stay away – then you need to go to work, to make the money, to help your parents – our children, in this country, they don't need to stick like it. Their job just to go to school, and that's it.
>
> Felicity: And then they can go to college –
>
> Margaryta: Yes, college and university… yes. Then after, they have problems like us! (*laughing*) But only, at the moment, GCSEs, I'm worried for my daughter, because I can see a few changes –she's very stressful, she's become aggressive, she says, "My brain's not working properly, I'm not thinking properly, I don't remember…!" and she starts to cry. And I say, "Calm down, do as much as you can…and don't do it all at once…".

Elise and Nicolae thought that mental health conditions could have both genetic and environmental causes, including stress due to lifestyle pressures. It was suggested by Nicolae that the extreme difficulties experienced by Roma people in CEE countries led sometimes to mental health conditions being passed psychologically through families. Marcin noted the deeply damaging impact on Roma people's health of the stress caused by marginalisation:

> Marcin: …you're all the time seeing someone who has a normal life, and you marginalised, and they have access to these, they have opportunities. Of course, this stress…you know, it makes you sick. I think that this is the worst, you know, part… the stress.

Daniella, aged 65, also identified the undesirability within Roma culture of speaking about emotional difficulties as a factor leading to worsening mental health and, through her interpreter, Katarina, highlighted this problem for Roma people in the UK:

> Katarina: The reason why it can be such a problem – she said that, like, a lot of people feel here alone, and no self-confidence - and also there's the cultural aspect. She said that it's not good to talk about problems, or complaining, so they're, like, keeping all these things in themselves, so it's not good for your mental health. What I think maybe also, she said that they feel maybe worse, it could be also because of this –
>
> Felicity: Oh, right… so they've got a problem, but then because they can't talk about it, it makes the problem worse…
>
> Katarina: Yes…

Echoing other participants, Daniella identified smoking as a common response among Roma people to emotional problems, describing it as an escape from nervousness. As with material causes, there was clarity among the participants that emotional difficulties contributed significantly to the development of mental health conditions and, also, to physical illness. Tobi et al. (2010) noted the strong emphasis on mental health in the literature on the health and well-being of Roma people. The impact of ongoing marginalisation, as well as cultural taboos, on the mental health of Roma people are discussed in Chapter six, in which concepts of culture, agency and identity offer readings of the findings alongside the literature from a post-structuralist perspective.

Physical problems

In addition, eight participants, including four aged under 30, identified physical problems, including chronic health issues, lack of exercise, obesity and overweight, as factors leading to new or worsening physical ailments and to a poor sense of well-being. Among a wide range of chronic physical conditions discussed by participants throughout the interviews, many were identified as notably contributing to poor long-term health and well-being. These included high blood pressure, heart disease, problems with cholesterol, kidney and liver problems, including kidney stones, recurrent chest infections, asthma, recurrent flu, headaches, ongoing pain caused by an accident, allergies, eczema, psoriasis, an ear and balance problem, and hearing difficulties. Some participants spoke of themselves, other family members, or their families overall, experiencing a number of these conditions simultaneously:

> Pansela: Well, it’s about me, my uncle *and* my Mum.
>
> Felicity: OK?
>
> Pansela: We need help – we’ve got health problems.

Pansela’s mother had, in fact, been taken to the hospital on the morning of the interview, as she was feeling unwell. Pansela explained that her mother suffered from ongoing cholesterol problems, due to eating fatty food, as well as an unrelated ear and balance problem, causing her to fall. Pansela, herself, had long-term health problems, which she felt posed a threat to her pregnancy:

> Pansela: …I had a miscarriage, and I’m pregnant three months now.
>
> Felicity: Ah. Right, so how’s that been? How’s your pregnancy care been going?
>
> Pansela: Oh, really well – just, I’ve got flu. Chest infection. Let me tell you – it never stops.
>
> Felicity: What doesn’t…?
>
> Pansela: My flu. It never stops. I can never –
>
> Felicity: You can’t get rid of it? –
>
> Pansela: Can’t get rid of it. That’s why…I know it’s bad for the baby…so I don’t know…

Another participant told a story about her husband, who had suffered for a long time from a hearing problem that had never been resolved:

> Dana: …he say, please you send me to specialist for hearing, because I’m no hearing properly. He say, you know, you must waiting for this, this is no for one month, two month, he’s maybe waiting two years…

Dana’s husband had been given penicillin, which he took for three or four months, to no effect. After two years, he saw a specialist, who diagnosed an infection affecting his hearing in one ear. At the time of the interview, Dana's husband remained unable to hear with the affected ear and had developed psoriasis, which Dana believed was caused by very strong doses of the penicillin.

Participants reported differing views regarding the prevalence of childhood hearing loss amongst Roma children, with Lavinia, Nicolae and Florin thinking that this was no different from that of children in other groups. Kristina reported that this was not a problem affecting children in her own family but did not wish to comment about other members of Roma communities. Artur, however, spoke of a hearing problem experienced by a younger sibling, and Mirabella's perception, which echoed research by Swanwick et al. (2018), was of broader difficulties among Roma children:

> F: …And then they think there might be a lot of…particularly a lot of hearing difficulties for children, Roma children.
>
> M: Yes, some baby have ear…some baby, you know, like you born a baby is like disability or something…there's lots, we have it…

A lack of exercise, obesity and overweight were also identified by participants as factors leading to poor health and well-being among Roma people in London, including children. Again, the move from a nomadic lifestyle to one of settlement was seen as contributing to a deterioration in health:

> Samuel: …the older generation used to travel. And for me travelling and walking was kind of exercise, and that keeps you fit, and that keeps you healthy. And they're not doing it that much now - nowadays the younger generation. And we didn't hear that much about cancers. We didn't hear that much about health diseases, they were dying in their eighties, nineties, and everyone is saying that people were just healthier. And now, they are really not well.

Samuel also suggested that, for Roma women, in particular, cultural factors added to these difficulties, although this educated Roma man's view was not discussed by the women in the study:

> Samuel: A lot of people are obese. Or overweight. They do not exercise as far as I'm concerned. Especially women. They do not go to gym. I can't say they're not allowed, but they wouldn't go. It's a little bit like the Asian community, unless the gym would be just for them, and there won't be any men, and they wouldn't have to dress dance. So, I know that it's easy to exercise in skirts, but I haven't heard of many Roma women going to gym.

Chronic health conditions and a lack of exercise were both seen by participants as contributing to poor health and well-being among Roma people living in London. Cultural factors also viewed by participants as problematic in relation to a healthy and contented life are discussed in more detail below. A wide range of chronic and other physical health conditions were also identified within the literature (Performance and Research Team, Sheffield City Council, 2015; Migration Yorkshire, 2012; Tobi et al., 2010). Within the literature, hearing impairment among Roma children was reported to be an issue of concern, in relation to the wider population (Swanwick et al., 2018; Willis, 2016; Performance and Research Team, Sheffield City Council, 2015). However, comparisons overall with the health status of members of other groups were rarely made and the significance of this, as well as the emphasis in the earlier literature on communicable disease, is considered in Chapter six.

Cultural issues

Among the factors attributed by ten participants to the development of poor health and well-being were cultural prohibitions regarding gender, mental health, disability and care of the elderly. Six participants from all countries represented spoke about the impact of Roma cultural factors on mental health. In addition, three participants spoke of a reliance on faith and churches to take care of health and well-being, particularly mental health conditions. Sisters, Margaryta and Elise, spoke about the inhibiting nature of cultural requirements regarding gender, and how these can lead to serious consequences in relation to the health of Roma women:

> Margaryta: Yes, it’s important, you know when you don’t speak very good English, and we are Roma people and we are a little bit shy, and you know, even if we are not well, we go to the doctor, if it’s doctor – if it’s not a lady doctor then you shy to say what’s wrong with you, lot of people, maybe they have infection, or some problem – breast cancer, for example - they not going to show to the doctor, because he’s male -
>
> Felicity: A man –
>
> Margaryta: Yes. He’s no female. And that’s very – I don’t know how to explain – people don’t understand. But this is how – we are like that. Shy to show – and people die, because they didn’t go to the doctor.

Although it was possible to ask to see a female doctor, not every GP practice was able to offer this. Elise noted that, if a female doctor was not available, Roma women preferred to stay at home. She described Roma women as ‘principled’, adhering to their cultural upbringing despite the dangers this presented to their health. Margaryta summed up the dilemma they faced:

> Margaryta: It’s wrong, but this is the way how we grew up.
>
> Felicity: It’s not wrong. Why is it wrong?
>
> Margaryta: Because, you can lose your life because of the culture…

The participants identified the use of accident and emergency departments as a solution, since more female doctors were likely to be working in the hospital setting. Echoing Samuel, Margaryta noted that people of other cultures have similar concerns:

> Margaryta: Because even Muslim people - they close to us – they more going to prefer to go to the lady doctor, than with a man.

The same difficulty could also present itself during childbirth in hospital. A female midwife would attend a Roma woman during a straightforward labour but, if she experienced medical problems, a doctor would be called. In this situation, a female doctor could not be guaranteed. The participants noted that Roma women prefer to have babies at home, to ensure a female midwife. However, Margaryta and Elise had differing experiences of childbirth, with Margaryta's children having been born in the local hospital in London, and Elise having had her children at home. In the case of a hospital birth, the participants reported that the safety of mother and baby would override the cultural prohibition:

> Elise: But sometimes, you know, sometimes something happens that you no expecting, and if you are in such a condition, and they have to give birth to the baby, and it happens such a thing, that the lady - the female doctor is busy, so you don't have no choice, so it's better just save my life, you don't think - after you know, you don't feel ashamed or something.

> Margaryta: I think, obviously every mum, they want to save the baby, they don't think - it's a natural effect, you know, it's a natural – it happens, they don't think nothing else… to save your baby even if it's somebody – you don't want to be dead – you know?

In relation to the impact of stress, the participants also talked about cultural factors preventing treatment being sought for mental health conditions. Mental health problems were described as a difficult topic for Roma families, due to the stigma they carried in Roma communities. These conditions tended to be denied or hidden from Roma people outside the immediate family. Adults suffering from depression or anxiety were unable to speak about, or seek help for, their illnesses. Participants described the invisibility of mental health conditions, a disbelief in their existence, and the resulting worsening of these conditions. Roma children, also, were unable to access treatment for mental health difficulties.

Shame, as evoked by Elise in relation to the breaking of Roma cultural taboos during childbirth, was also associated with mental health problems. Speaking very quietly and thoughtfully, Margaryta and Elise noted a particular difficulty for Roma women:

> Margaryta: You know this is… in our Roma culture, is very shameful to say the ladies – men's maybe a little bit easier than woman, that you know well... that they have mental problems…

> Elise: It's like shameful, you know, it's more like something shameful.

The participants described Roma people in small communities as lacking the education that would enable them to understand the need for compassion, respect and treatment for people suffering from mental health problems, particularly women. Mental health conditions were equated with a lack of ability, and a daughter of a woman with mental health problems would be seen as unmarriageable, hence the denial and hiding of these issues. Mental health problems were traditionally viewed as genetically caused and, therefore, a threat to future children. However, Elise and Margaryta believed that the causes of mental health problems could be genetic or environmental:

> Elise: Some of them genetic, some of them happen, you know? Because people going through a very hard life…isn't it? Through the hard life, and stress, and after, you don't know, it just happens slowly, or something…

> Margaryta: …And just small thing can affect the health, of course, and it doesn't mean that her daughter's going to be like that.

Although many participants of the present study had access to the charity's Roma mental health advocacy project (RSG, 2012; Zawacki and Ferranti, 2021), the impossibility of finding help for mental health issues within this scenario meant that Roma people, in a general sense, were described as suffering on their own, with problems being compounded by the negative way in which they were regarded. Participants reported that Roma people would often make fun of those with mental health difficulties and described a strong cultural fear of being laughed at, and of humiliation. Nevertheless, the participants noted that Roma people in this situation would usually be taken care of within their immediate families.

This cultural taboo regarding mental health issues also applied to disability. Samuel described its functional nature:

> Samuel: …definitely in the Roma community. Having a disabled child or a child with a mental health issue, it is a little bit taboo.
>
> Felicity: Why is that?
>
> Samuel: I don't know. I just simply do not know. But – [ever] since I remember, those subjects are very often hidden. They do not talk about this, they do not want to admit it, even if they are adults and they suffer from depression or anxiety, they'd rather not discovering it. They prefer to keep it quiet. Maybe there is a stereotype in Roma culture that men have to be really strong, and they have to be clever, and also the women have to be strong. Provide food for the family, take care of family, and there's no room, there's no place for being weak. And if you're having a mental health issue, it's considered like you are weak. If you're depressed, it's the equivalent of being weak.

Participants felt that Roma people were gradually becoming more aware of mental health conditions as treatable but saw this change as a slow process. In relation to disability, Paulo described his fears for his son, who had learning difficulties:

> Paulo: …And the problem is, my son he is sick, he can't talk. So, I can go here, I'm think they can maybe tease him, maybe they can, like, "Oh you can't talk…you can't…this, that…" you know?

It was noted by participants that some Roma parents would conflate conditions such as autism and mental health issues, resulting in the denial of the condition and an avoidance of treatment. Learning difficulties, autism or physical disabilities could all be worsened through a lack of attention, and this applied to both Roma adults and children. [1]

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[1] Between July 2016 and February 2017, the present researcher undertook weekly voluntary work with the mental health project run by the charity. The issues described by the study participants in relation to mental health, disability and Roma culture very much reflected the profound difficulties expressed by the clients of

Agata, who was Polish, also spoke about the care of older Roma people. Although most were looked after by their own families, the pressures of life in the UK led to some living in care homes. Cultural taboos, regarding personal care of the body, were reported as leading to neglected hygiene, as older Roma people would not be able to allow someone from outside their family to bathe them. Agata's interpreter, Elena, expressed surprise, herself, at this significant change:

> Elena: So, it means they don't look after parents, grandparents -?
>
> Agata: - look but not like before. The time is running too fast.
>
> Elena: But they are left on their own? *(Polish)* So, even it happens, what was impossible even to think, in the old days, to leave parents in the, how they are called, places for elderly people –
>
> Felicity: care homes…
>
> Elena: Care homes, yes. So even now, the Roma people, you know, do that.
>
> Agata: It's happening, not often…but sometimes…

Finally, a reliance on religious faith and churches to take care of health and well-being, particularly mental health, was described by three participants as a contributory factor in worsening health conditions. Participants reported the difficulty for Roma people in accepting mental health conditions leading to delayed treatment. Instead, family members hoped to protect the individual concerned from the negative response of the community through seeking help from churches. In addition, when describing the commonly perceived unhealthy Roma lifestyle, it was suggested that Roma people were aware of this but chose to place their faith in [in this case, a Catholic] God, to determine their fate, rather than changing their behaviour.

Overall, it was clear from the interviews that cultural prohibitions and taboos had a profound impact on poor health and well-being among Roma people, and that these difficulties

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the charity during the period of voluntary work. These are highlighted in the Guidelines for healthcare practitioners (Appendix P).

continued, following migration to the UK. Nevertheless, there were indications within the findings of participants taking up differing positions in relation to the demands of Roma culture in the context of health and well-being, and of cultural adaptation to new circumstances. However, viewed from an intersectional perspective (Crenshaw, 1991, 1989), Roma women appeared to occupy a place in which being subject to prejudice as Roma combined with the restrictions of Roma cultural taboos to negatively impact their health and well-being. In the context of migration to London, cultural prohibitions that may have had functional origins during nomadic Roma history served to inhibit the access of Roma women to healthcare services. Margaryta and Elise's discussion of shame in relation to childbirth, the inability of Roma women to disclose symptoms to male doctors, and their linking of mental health conditions to women as the supposed carriers of genetic disorders, all added to a combination of difficulties experienced by Roma women in the UK healthcare context. Within the literature, a large number of reports noted the significant impact of issues relating to culture on health and well-being outcomes for Roma people (Marsh, 2017; RSG, 2017, 2016, 2015; The Social Marketing Gateway, 2013; FRA, 2012; RSG, 2012; Tobi et al., 2010; Poole and Adamson, 2008; Zeman et al, 2003; Hajioff and McKee, 2000). Many of these reports presented a picture of Roma culture as static, and of a need for services to adapt to this. The complexities, and influence, of differing discourses relating to Roma culture and health are noted in Chapter six, using a concept of culture that has, itself, been problematised by post-structuralist thinking.

Broader social factors

The experiences of the Roma participants took place within the context of broader social factors, some of which were reported as contributing to poor health and well-being outcomes. These included centuries of ongoing prejudice and discrimination towards Roma people, the effects of media representation of Roma people, the initial impact of the UK Brexit referendum, and a lack of dedicated support for Roma people around health and well-being.

Four participants referred to their experiences of discrimination in Poland and Romania, often in relation to accessing healthcare services. Marcin described the way in which Roma people were treated differently from others in Romania, within a healthcare system where payment was required for medical treatment. A lack of education that prevented them from fully understanding the process left Roma people at risk of exploitation. Participants contrasted these experiences with the ways in which they perceived the situation in London. For some, the cosmopolitan diversity of London offered a refuge from the visibility of Roma people in Central and Eastern Europe:

> Samuel: …The good thing here is that I do not, or my family, they do not - are not that visible. Because Roma people in Eastern Europe are highly visible. So, every time they are going to a GP or a hospital - maybe not every time – but… they also witness Polish doctors and nurses being racist. And because we are here in London, we are here in the UK, we are one of many other cultures. It's much easier to blend in. So that's a good thing.
>
> Felicity: OK, so that's interesting. So, in a more diverse culture, you feel that it's easier –
>
> Samuel: It's easier and safer –

> Nicolae: …at least at the first meeting, that person will not assume that – from the first moment that you're Roma… and therefore they feel that it's much better here, because they can just mix with everyone, and it's easier to get a job, it's easier, you know, to send your kids to school.

Other participants, however, reported experiences of prejudice and discrimination in London, which contributed to a poor sense of well-being. Dana, the study's only Slovak participant, described being unable to take time off from work in a factory while she was pregnant. Despite having worked in the job for several years, when unwell with complications during her pregnancy, the participant was threatened with the loss of her job, if she took any time off. Dana's experience reflects the observations of Nagy (2018), within the context of labour exploitation of Roma migrants. Other participants reported experiences of prejudice that frightened them or made them resort to hiding their Roma identity:

> Margaryta: …you know, people, I listen one Roma song, and I was working as a carer - I have lots and lots of jobs! …So, the guy heard the song, and he said, “Are you Gypsy?” But in the way, not happy way. I said, “No, I’m not.” Because I didn’t want to affect my job…
>
> Felicity: How did he know? …
>
> Margaryta: By the song… In my phone. It was some Romania, new group… I like it, the beat, and – I put it, because I was cleaning in the house. And, er, the guy who work with me, he said, “Oh, I’ve heard this tune, it’s nice, but how come you know this song? Are you Gypsy?” I said, “No, I’m not”.
>
> Felicity: So, you hid it. How do you feel about that?
>
> Margaryta: I didn’t feel nice, you know? So that means that they have no respect. They say, oh, Gypsies doing bad things. No, I’m a Gypsy myself, and I’m working. I don’t choose - carer, market, any job, even cleaner, doesn’t matter. All jobs… But I see lot of different things.

Participants noted that traditional Roma people arrive in the UK with the assumption that they will be discriminated against, based on their past experience. Any negative experience, such as a GP being too busy to see them, will be understood as discriminatory. One participant commented on the representation of Roma people as thieves, by elements of the British media, as leading to a perception of the Roma as untrustworthy. This attitude of mistrust was described as worsening, following the 2016 UK referendum vote to leave the European Union, and participants reported increasing difficulties for Roma people in obtaining National Insurance numbers, bank accounts and official documents. The effects of these aspects of the wider societal picture were also discussed in the literature, which identified negative media coverage (The Social Marketing Gateway, 2013), changes brought about by Brexit (Morris, 2016), and the impact of ongoing racism, prejudice and discrimination on mental health (RSG 2017, 2016, 2015; EPHA, 2014; Lane et al., 2014; Greenfields, 2012; RSG, 2012; Tobi et al., 2010; Zeman et al., 2003) as significant factors affecting the health and well-being of Roma people in the UK. Narratives relating to the marginalisation of Roma people, and its impact on their health and well-being, are problematised in Chapter six, using the concepts of culture and nomadism.

The difficulties also involved in obtaining British citizenship were described by a participant who appeared confident and had a reasonable grasp of the English language. This participant had spent a considerable amount of time helping Roma people with less English to deal with the bureaucratic complexity of the process. Despite the reporting of some positive attitudes, the emotional impact of the referendum outcome was taking its toll:

> Paulo: …But now, it's happened, Brexit, you know, I'm like, worried, you know? Maybe in one year I have to go back…it's like, take a lot of, I'm think many people get depression – and they had it from Brexit, you know? I know many people from different countries and they're, like, scared now.

> Mirabella: …because all this is coming after we had the UK want to leave Romania out, after that, people different now. It's changed. They're saying, "Soon you're going out from here…" Because I am out on the street. I have lots of people talking… horrible things to me and good things -
>
> Felicity: Do you?
>
> Mirabella: They're saying, "You're from Romania, you're Gypsy – you're going out from here" …yeah, they're saying… [2]

Although life in London was, in some ways, easier for the participants than life in their home countries, the broader social context in the UK was challenging and potentially damaging for their health and well-being. Notably, there was very little dedicated help. Most support came from within the communities themselves, or from non-governmental agencies:

> Felicity: - you speak very good English, you have British citizenship, it's still a problem –

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[2] An increase in reported incidents of hate crime against Gypsies, Roma and Travellers, following the Referendum, was discussed at the Traveller Movement Conference in London in November 2016. It was noted that this occurred within a shift towards the political right across the whole of Europe.

> Margaryta: - yes… still… because I think they're going to see me in a different way – you know, Romania, Roma people, they begging, and on this, they come to me, and I give them my cost price, because I know they can't afford to buy… then I speak in the same language, people see me – I don't mind… I don't mind. Because they can't speak English, they speak Roma, they want to buy, or they ask me, if they need doctor or something, I send them here [to the charity]. I give the address, and I say, come here for help. Because this is the only place who can help Roma people.

A lack of dedicated support for Roma health was linked in the literature to the absence of any UK-wide strategic policy (European Commission, 2017; National Roma Network, 2017; Shallice and Greason, 2017; Willis, 2016; Clark, 2015; Migration Yorkshire, 2012; Fremlová, 2009; Fremlová and Ureche, 2009). The absence of strategic healthcare policy for Roma people in the UK is discussed in Chapter six, in relation to the categorising of Roma people as vulnerable or 'hard to reach', and the ensuing lack of data regarding their health and well-being. The impact of marginalising narratives about Roma people, and the possible significance of their nomadic histories, are also considered from a post-structuralist perspective.

Table 4: Theme 2 – Barriers to accessing services and treatment

Theme 2	Sub-themes and codes
Barriers to accessing services and treatment	**Communication difficulties** Language barrier, difficulties in understanding medical terminology, basic level language classes too difficult, language barrier to talking therapies, problems with interpreting services **Educational issues** Low educational levels, lack of knowledge and information, inability to access information, lack of confidence, talking therapies a new concept for Roma people **Cultural factors** Cultural taboos around health and well-being, cultural factors regarding interpreting, gender and age, taboos relating to mental health and disability **Service accessibility difficulties** Difficulties in making GP appointments, especially when children are unwell, long waiting times to see specialists, problems with cancellations and changing hospital appointments, return to country of origin for medical treatment, despite need to pay

In response to a question about barriers to accessing health and well-being services in London, the participants spoke of a range of difficulties. Their replies were organised under four sub-themes: communication difficulties, educational issues, cultural factors, and service accessibility difficulties.

Communication difficulties

Sixteen participants reported communication difficulties as the greatest challenge facing members of Roma communities in London, when seeking access to healthcare services. Participants spoke of their own difficulties on arrival in the UK, and those of family members. For some, these difficulties were alleviated through an improved grasp of the English language but, for others, communication in English remained problematic many years later. Although it was not possible to generalise from the relatively small participant cohort of the present study, there were indications that factors relating to gender may have contributed to ongoing difficulties in learning English. Two participants one Romanian and one Polish, who reported themselves as becoming informal interpreters for the wider Roma community were male, as were two participants who were working in a professional capacity with other Roma people. In the latter case, these participants, also from Poland and Romania, had received further or higher education in their countries of origin, prior to their arrival in London. The informal interpreters had each been in the UK for 18 years, and the professional staff for four years.

None of the study participants had been born in the UK but Artur and Pansela, who had arrived as infants, did not refer to communication difficulties as a problem for the community, although they discussed many other problems in relation to health and well-being. However, another participant reported an older relative, who had lived in London for almost four years, as remaining unregistered with a GP. The relative was said to be afraid to go because he did not speak English. This participant, who worked with other Roma people, believed that many Roma people in London and the rest of the UK were not registered with a GP. Daniella, who arrived at the age of 47 and had been in the UK for 18 years, spoke through her interpreter, Katarina, of continuing difficulties:

> Katarina: Sometimes she finds it – she spends most of the time at home, so when she has to go somewhere, she has to have some assistance, and she's not self-confident, and yes, she said that may be because of the language barrier, also.
>
> Felicity: OK, ok. So, if you ask for an interpreter, what happens? What's your experience of interpreters?
>
> Katarina: From her experience, it's very difficult to get the interpreter, and when she can't have the interpreter, so she just, like, can't go anywhere, without…

Participants described the provision of interpreters within the health service as being very inconsistent. The availability of interpreters was reported as differing with different GPs, and participants spoke of difficulties and delays when trying to book interpreters for appointments with specialists. Although participants' English competency was often adequate for routine healthcare visits, understanding medical terminology continued to present problems. Participants reported healthcare staff assuming their English to be adequate when, in fact, they needed language support for conversations about complex medical conditions. Some participants reported specific health-related problems that had been caused, or worsened, by unsatisfactory interpreting and translation services. [3] Kristina's experience, recounted with the help of her interpreter, Maria, highlighted a more general difficulty, suggesting possible prejudice on the part of another Polish interpreter:

> Maria: So, she has one example, of problems with an interpreter, she had an interpreter booked for the visit and she asked the doctor to explain one more time, and the interpreter interfered, asking her, the patient, why she asked the question again, to answer, and if she was sure she wanted to ask again, and she explained yes, because I didn't understand, and I want to ask again. I want the doctor's explanation… So, the doctor realised that there was something wrong, and she asked, "What was that about?" and Kristina explained the

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[3] At the Roma Refugee and Migrant Forum meeting in East London in January 2017, Forum Theatre (Boal, 1979) was used as a technique for involving Roma people in finding solutions, alongside health professionals, for difficulties experienced with the use of interpreters. Through audience participation, professionals were able to understand how interpreting services within healthcare might be improved for the benefit of Roma patients.

> situation, in English, and the doctor told the interpreter that the interpreter's role was to interpret *everything*, *every* question.

Where interpreters were available, participants reported that these would be speakers of the languages of their countries of origin. While this was satisfactory for some, others needed interpreters speaking the Romani language:

> Felicity: …are there any other difficulties with accessing health services?
>
> Margaryta: Language.
>
> Felicity: Language, yes.
>
> Margaryta: Yes. Because, Roma people - is no interpreters for Roma people. They think if you're Bosnian, they bring Serbo-Croat interpreter. But some people, they don't speak [it]. Like my children. My children speak Roma Gypsy language or English. They don't speak Serbian. Because they didn't learn it. They learnt Roma language - is our house language. The spoken language we speak in the house, and Serbian is the one you learn in the school. Like English here. So, because they're born here, they use more English than even Roma language. So, what about the other people? The old people, they come, they can't speak English…so they speak only Roma.

Margaryta noted that Roma people needed to trust an interpreter and thought they would feel comfortable with one who was Roma. Interpreters speaking the Romani language were, however, not readily available. Marcin told how, when his family was first learning English, their interpreters always spoke Romanian:

> Felicity: And that was alright? The interpreting?
>
> Marcin: It was OK
>
> Felicity: In Romanian –
>
> Marcin: In Romanian – in Roma language it's difficult to find an interpreter - I am the one (*he laughs*) I am the one…

For Agata, with her interpreter, Elena, the lack of educational opportunities for Roma people left them in a difficult situation regarding communication with healthcare professionals:

> Elena: She says that because, you know, like, Roma are very low educated… they don't know how to communicate. Even in the Polish language - so there is also barrier, between you know, Roma people and Polish interpreters for example. She said when she goes for appointment with her mum, when Polish interpreters said something, mum didn't understand, so basically Agata might have to, you know, like, explain – in Romanes [Romani language] what it means – [4]

Agata had attended English language classes in London when she was working but reported even the basic level classes as being too difficult, as she was unable to read text written in Polish. In addition, when she had health problems at a later date, she had forgotten many of the English words she had learnt. Participants also reported an inability to speak English as being, clearly, a barrier to accessing talking therapies, even though these therapies were free of charge.

Although one participant believed that interpreters were now more readily available for Roma people than they had been in the past, the overall picture painted by participants' responses was less positive. An inconsistent interpreting service resulted in difficulties for individuals, including children, who had to take time away from work or studying, in order to interpret for family members. For many Roma people, a lack of education left them in a vulnerable and precarious position when they needed to speak English, following migration to London, and this had a negative impact on their access to health and well-being services and treatment.

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[4] The present researcher attended a peer support meeting at the charity in September 2016, at which issues arising in relation to interpreting services were discussed. The difficulties reported by participants of the present study reflected those raised at the meeting by Roma clients. However, within the findings, there was greater diversity of views regarding the use of Roma interpreters. To some extent, this reflected language, rather than cultural, needs.

Within the literature, language and communication difficulties were also identified as a key barrier to accessing healthcare services for Roma people in the UK (National Roma Network, 2017; Shallice and Greason, 2017; Warwick-Booth et al., 2017; Brown et al., 2016; RSG, 2016; Willis, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2015; McNulty, 2014; Wright, 2011; Tobi et al., 2010; Fremlová, 2009; Fremlová and Ureche, 2009; Poole and Adamson, 2008). Nevertheless, the voices of Roma people themselves were not well represented in the literature (McFadden et al., 2018). In the next chapter, the importance of the voices of the Roma participants in articulating the subtleties of their experiences relating to health and well-being in London is considered, using the concept of voice as understood by post-structuralism.

Educational issues

In addition to difficulties with communication, this lack of educational opportunity led to further barriers for Roma people in London, in relation to their health and well-being. Seven participants reported low educational levels leaving Roma people unable to ask appropriate questions about healthcare issues. Of these, five were among the older members of the cohort and were from Poland, Slovakia and Romania. Four of these participants were women and the other was a male informal interpreter. Two younger men reported on their professional experience with their Roma clients. There was a lack of knowledge and information regarding the availability of, and access to, services and support, with advice being sought orally from older, respected relatives. Roma people were often unable to read letters, and most did not use the Internet or attend training courses. This lack of knowledge had implications regarding Roma families' access to support for health conditions, often those concerning children. One participant spoke about a Roma parent who was unaware of the meaning of an invitation to an individual meeting at her child's school:

> Nicolae: …for example, someone has a kid with a mental health condition, and came here three months ago, they registered this kid to school, they received a letter to go for some parents' meeting - which she would have never received if she was in her own country - and she was, you know, just looking at the letter and had no idea what does that mean, and how's that going to help, and why.

Nicolae noted that an individualised approach to children's special educational needs did not exist in Romania, this parent's home country, where parents' meetings would not address specific issues. Without support to bridge this cultural gap, parents might not attend a school meeting, assuming it to be of a generalised nature. Dana spoke of her own limited understanding of her son's autism diagnosis, and it was only through the advice of Roma friends that she had been able to locate a specialist. She also reported that she and her husband were unable to understand the outcome of her husband's hearing test, having waited two years for the assessment. In this instance, an interpreter had not been provided but one participant suggested that, where interpreters were available, they needed to be better informed about health and well-being services. The idea was that interpreters could offer factual information to Roma people. Although this would be outside an interpreter's remit, it speaks of the absence of advocates or, possibly, mediators to help Roma people find their way through the complexity of the health services in London, and to address their lack of relevant knowledge. Critiques of the use of Roma health mediators were, however, discussed in the review of more recent literature (Petraki, 2020; Kühlbrandt, 2019).

Participants reported further educational barriers, in relation to particular aspects of health and well-being. For example, Samuel spoke of a lack of prior education making it difficult to train Roma people in preventative medicine. However, Samuel thought that more educated young Roma people may see different lifestyles and start to do things differently. Roma people living in London faced a striking degree of difficulty, and often lacked confidence, due to these limited educational opportunities and the resulting complex language barrier.

Although providing education about health and healthcare services appeared in the literature, in relation to strategies for promoting improved access to services, this aspect was less prominent where barriers to access were discussed. Whilst Tobi et al. (2010) and Sheffield City Council (2015) noted difficulties in this area, in terms of barriers, the literature tended to focus on cultural factors, prejudice and discrimination, practical difficulties, and language and communication difficulties. Discourses about Roma culture and the locating of difficulties with Roma people themselves, rather than within broader social and cultural contexts, are discussed in Chapter six, using the concepts of culture and identity, as problematised by post-structuralism.

Cultural factors

Just as a lack of education could disadvantage Roma people, cultural factors also played a part in limiting successful access to healthcare services and treatment. Twelve participants, women and men, across the age range and from all the countries represented in the cohort, described Roma cultural taboos around health and well-being acting as highly significant barriers to service accessibility. Health in general was said to be a sensitive subject for Roma people, with health problems being difficult to talk about. Nevertheless, there was diversity among the participants' personal positions in relation to cultural demands:

> Magdalina: …depending [on] the people, because some people of Roma maybe they have some problem, but they don't talk. You know, some people of the Polish as well…
>
> …because, for example, if *I* don't know something, I look for someone who can get help for me, and, we do the same thing…

The four male participants who worked professionally with Roma people, or who acted as unofficial interpreters, spoke of the general Roma population as being subject to cultural taboos but one spoke of himself as being personally unaffected by cultural factors regarding health:

> Nicolae: …from my personal point of view, access to health doesn't affect anything – doesn't involve any of my cultural background or something like that…but I do know that for other Roma persons, health is quite a sensitive subject, and some people might…decide not to go to a doctor if they have some problem.

When speaking about culture in relation to factors impacting on health and well-being, participants emphasised the impact of cultural requirements on Roma women. Similarly, gender and, also, age were prominent among the ways in which cultural factors acted as a barrier to access. In addition, for many Roma people, access to healthcare provision was dependent upon adequate interpreting services. However, participants noted many difficulties regarding Roma cultural taboos affecting interpreting, particularly when the interpreter was a family member:

> Felicity: …And would it be appropriate always, for your son to interpret? Especially around health issues?
>
> Katarina: She [Daniella] likes more to use the interpreter than her son. If you ask about health services, sometimes he can - her son can help her, and sometimes he can't, because maybe there's a lack of language too, so…
>
> Felicity: And are there certain things that you wouldn't want to discuss in front of your son?
>
> Katarina & Daniella: Yes, yes. She prefers a woman to be with her in this case.
>
> Katarina: … and for a woman it [a Roma interpreter] has to be a woman.

> Felicity: … you talked about when you were interpreting for your sister, as a male relative –
>
> Florin: Oh yeah, being a male interpreter was a bit of a taboo before in the Roma culture. This is why there are not too many Roma interpreters, to go to the doctors, because – a male – as I say - a man can't translate for a female. You know, if they just have a cough, but if they talk about something different, which is really asking other questions, they are taboo, so we cannot talk about it. About something…different…

While Florin believed that these issues would be problematic in any culture, he thought that an actual prohibition was specific to Roma culture. Marcin, also, stressed the specific restrictions facing Roma women who needed to access healthcare services:

> Florin: … you know – in any culture, if a male translates for a female, a lady, where she has, like, proper female problems, and she has to speak about her body, or something, obviously that would feel uncomfortable, but if you have to, you have to. We cannot.

> Felicity: So, a Roma man translating would be the worst, for a woman-
>
> Marcin: -for the woman, yes – the Gypsy woman yes, they don't want to say –
>
> Felicity: - and that's a cultural thing…
>
> Marcin: - if it's something like that. If it's something else - from here - (*indicating the upper part of the body*) they will say everything (*his wife agrees)*
>
> But if it is from here down, they're not going to say. Something for birth, not much communication for the man, but if it's a heart problem, mind problem, anything. But, you know, intimate parts, they're not going to say nothing. Not much communication for the woman.

Despite some divergence between male and female participants, as to whether or not a Roma woman might be able to speak easily to a male non-Roma doctor, the responses overall powerfully stressed the strength of cultural prohibitions regarding gender, and the impact of this on Roma women who needed an interpreter in the healthcare context. Eight participants also noted a more general Roma taboo against talking about health, particularly affecting elderly Roma people.

Access to mental health services and support for disability were restricted, with mental health issues and disability consistently being reported as particularly taboo subjects. Participants described difficulties in speaking about emotions and reported mental health issues as being discussed only within the very close family. Debora noted the cultural shame attached to mental illness and to drug taking, while describing herself as more open than others in her community.

Although it was not possible to generalise from the study cohort, there were indications that gender, age and educational status may have influenced participants' experiences of cultural factors as a barrier to accessing healthcare services. Whilst this reflected the strong cultural demands placed on Roma women and older people, the participants' responses included a degree of diversity, and an indication of the impact of change on tradition.

Within the literature there was a strong emphasis on the impact of Roma culture on health and well-being outcomes (Marsh, 2017; RSG, 2017, 2016, 2015, The Social Marketing

Gateway, 2013; FRA, 2012; RSG, 2012; Tobi et al., 2010; Poole and Adamson, 2008; Zeman et al, 2003; Hajioff and McKee, 2000). Nevertheless, a healthcare policy focus on Romani women, in relation to Romani culture, was critiqued by Acton et al. (1997), as over-simplistic, and Smith and Newton (2016), found the importance of structural factors in affecting health-related decisions made by Gypsy, Roma and Traveller people to be underestimated. In addition, Clark (2014) noted the limitations of viewing Gypsies, Roma and Travellers purely from a racialised and ethnicised perspective. The responses of the participants suggested the appropriateness of a more nuanced approach to the role of cultural factors in relation to Roma people's health and well-being. In Chapter six, the concepts of culture and agency are used to problematise discourses about Roma culture that fail to recognise the individual agency of Roma people, and processes of cultural change and exchange.

Service accessibility difficulties

In terms of the healthcare services themselves, eight participants were highly critical of the difficulties experienced in obtaining appointments to see a GP. Long waiting times and queues were reported, as well as short appointments. There were particular concerns with regard to booking appointments when children were unwell. Often, a GP did not examine the child, simply relying on a verbal description of the symptoms, and asking parents to wait for two or three days. Participants reported worsening symptoms in both children and adults, and the accompanying anxiety, as leading them to turn to accident and emergency departments, where they would be seen on the same day. However, for some, there was a lack of optimism regarding the outcome of a long wait:

> Nicolae: You know, I've worked on construction sites, in the UK, for three years, and I met people from all sorts of backgrounds, Romanians, you know, Roma, non-Roma from all sorts of backgrounds, from villages, from big cities, small cities, whatever, and you know, the common feeling that people have is, if you go to hospital in the UK, in London, it's useless doing it. This is what people feel. I go to a hospital in London, I stay there for there for five hours, and they'll give me a Paracetamol.

Four participants also described long waiting times to see specialists, with one participant reporting waiting over a year for surgery, and another waiting for two years for an examination. Long waits for test results, and for access to gynaecological and psychological services, were reported. One participants experienced problems when needing to change hospital appointment times, describing being discharged after cancelling her own appointment, so she could accompany her mother to another. These problems, however, were not necessarily Roma-specific.

Comparisons with service accessibility in participants' countries of origin differed. It was suggested by Samuel that Roma people preferred to go to Poland to see a doctor if they were seriously unwell. Roma people were said to return to Poland for healthcare because of the language and because they know the system. The need to pay for healthcare in Poland was compensated for by shorter waiting times. By contrast, although it was said by Nicolae to be unusual in Romania for Roma people not to have a GP, access to specialist help in Romania was difficult for Roma people, due to the public system of health insurance. More positively, one participant noted that, in Romania, hospital results could be obtained on the same day, rather than after two or three months as in the UK. Nevertheless, she recognised that waiting times were longer in the UK because the services had to provide for more people.

Despite the accessibility difficulties reported by the participants, Magdalina believed that healthcare for Roma people had improved with access to professional services. Florin looked to the wider context of the healthcare services themselves:

> Florin: It is problematic. I've been thinking about it, and I really think it's not about money, it's not about understaffing, it's about the whole environment, the whole working thing, they don't see a patient - I feel like that – I can't say that about everyone – I feel like they don't see a patient, they see a number and a name… so, I really don't know how to say that, but I think that, the problem is that they need to see a patient, not a form. Or a number. That's only my opinion.

In the literature, practical difficulties in accessing health and well-being services were discussed (Marsh, 2017; RSG, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2015; Lane et al., 2014; Wright, 2011; Tobi et al., 2010), with the FRA (2012); Fremlová (2009) and Fremlová and Ureche (2009) noting a perception among Roma people of inadequate services. A smaller number of articles commented on the ongoing funding crisis facing the NHS, within which Roma people were accessing services that were, themselves, under pressure (The Social Marketing Gateway, 2013; FRA, 2012; Poole and Adamson, 2008). Once again, comparisons with the experiences of non-Roma people, whilst mentioned by Nicolae, were absent from much of the literature. In addition, Florin's critique of the UK healthcare services themselves opens up a different narrative about the relationship between Roma and non-Roma patients, and the accessibility of healthcare services, in which a more generic criticism is voiced, looking beyond the specific Roma experience.

Table 5: Theme 3 – Experiences of health and well-being services

Theme 3	**Sub-themes and codes**
Experiences of health and well-being services	**Prejudice and discrimination** Prejudice and discrimination on the part of some healthcare professionals **Negative experiences of services** GP appointments too short, GP experienced as not listening, waiting times becoming longer, overcrowded hospitals, dissatisfaction with treatment or medication received, difficulties judging when to go to pharmacist and when to go to A&E, variation between services in different areas **Positive experiences of services** Positive experiences of maternity services, good support for pregnant Roma girl under legal age of adulthood, positive experiences of healthcare for Roma people, perception of healthcare provision as equitable for all, some find talking therapies helpful, some positive experiences of GPs, use of A&E if appointments unavailable, hospital staff experienced as more welcoming than GP Differing views, differing experiences

The participants' responses contained many positive, as well as negative, experiences of health and well-being services in London. A particular focus, however, among negative experiences, was on prejudice and discrimination on the part of some healthcare professionals.

Prejudice and discrimination

Although by no means the whole cohort, eight participants reported experiences of prejudice in London healthcare settings, attributing this to their lack of proficiency in English, immigrant status or Roma identity:

> Pansela: Well – because my boyfriend is *English*, and I'm a *Gypsy*, so when I go with him, GP, I can actually see he gets more care than *I* do…
>
> Felicity: Right…
>
> Pansela: So, it looks really different. Because they talk more to English people than to Gypsies.

Daniella linked her difficulties with learning English to feeling poorly treated in London:

> Katarina: She thinks that maybe she would be treated better if she were British or …
>
> Felicity: OK. And what sort of experiences have you had, that make you think that?
>
> Katarina: She felt like an outsider, or someone standing on the third level, not the first one, and…
>
> Felicity: OK, that's interesting. And who would be on the second level?
>
> Katarina: She said someone who can communicate better. Who can, like, be in charge of the case, who can manage…
>
> Felicity: OK. You're saying that after 18 years…

Other participants recounted particular experiences, which they had clearly found very distressing. In one case, a participant had asked her GP for a cream for her son's eczema but had been prescribed a cream for the whole family, for a contagious condition. Whilst this may have been necessary, the participant was very upset, as she felt she was being accused of being unclean. Another described what she said was her first experience of prejudice, when nurses called her 'a Romanya', after she checked her hospitalised mother's medication. In both cases, the participants were highly sensitive to being seen in a bad light as Roma people.

Debora's story highlighted the dangers associated with possible prejudice, when she was asked if she was from Poland, while seeking help for her son, despite paramedics having seen a need for him to be taken to the hospital:

> Katarina: OK, so the situation with her son, it was in the middle of the night, and he had really a fever, like, 40°, so it was quite high and serious, yes…so she called for an ambulance, and they were very quick, and they were trying to help him. It was a person who was trained for first aid –
>
> Felicity: - paramedic
>
> Katarina: Yes, paramedic, so they gave him cold towels, and something for the pain. But when they were in the hospital, the doctor was like, she's not racist, but she remember exactly that he was from India, and he asked her why they had called for an ambulance, because maybe someone needed help at that time, and there's no need to come to hospital. And he gave him only Paracetamol, and he said, "I won't talk with you," and they sent them off. So, they were trying to do something on their own, to help her son –
>
> Felicity: But you'd done that because you were frightened, really…
>
> Katarina: Yes…and after that, they came to the same hospital, and the doctor was different, a British woman, and she said, "Oh why didn't they give him antibiotics?" and she checked the name of the doctor, and she said to her that she can make a complaint, because of this, because it was her son, and it was like, even, a risk of death…
>
> Felicity: So, what age was your son?
>
> Debora: I think he was about fifteen…

These experiences reflected negative views of Roma patients, reported in the literature by Poole and Adamson (2008), as well as some uncertainty regarding the responsibility of healthcare professionals towards Roma people (The Social Marketing Gateway, 2013; Wright, 2011; Poole and Adamson, 2008). Narratives contributing to ongoing prejudice and discrimination towards Roma people are problematised in Chapter six, using the concepts of culture and nomadism.

Negative experiences of services

Sixteen participants also reported more generic dissatisfactions with healthcare services in London, including a differing quality of service in different areas. Problems with GP practices were frequent. The participants spoke of long waits for appointments, short appointment times, feeling not listened to and wanting more time to talk. One reported seeing different GPs during a long wait to see a specialist; another felt let down by her GP, who was unable to help with a complaint that led to emergency surgery. This participant said she felt as every patient would, rather than simply as a Roma person. In another case, a participant had concerns about the field of experience of her GP.

There was also a general dissatisfaction with regard to the treatment offered in the UK, both by GPs and by hospital staff. Echoing Nicolae's earlier comment, four participants complained about being given Paracetamol for many health conditions, a treatment they felt to be inadequate in comparison with care received in their home countries of Romania and Poland. In relation to this wish to be offered more, Nicolae also spoke about a general desire for antibiotics:

> Nicolae: …what I've noticed is, for example, in Romania if you go to your GP, it [she or he] will give you tons of antibiotics, which doctors, GPs are not doing here. And which I find it good. Because people just take so much antibiotics, and I think they can end up taking so many antibiotics, it's just leading to not having any effect on you. Which I think is good. But on the other hand, this is what people believe, that they're not treated well.

Although Nicolae could see the reason for restricting the prescription of antibiotics, he also understood Roma people's frustration with being offered Paracetamol as an alternative. He described the way in which they would then buy antibiotics from Romania, without medical advice, some of which could be purchased from pharmacies by relatives.

In relation to London hospitals, participants reported overcrowding, waiting times becoming longer and poorer services more recently. Debora's experience with her son had reflected the current pressure on hospital resources. Florin was particularly thoughtful about the context in which Roma people were seeking healthcare in London. He spoke of the tension between policies devised to minimise waste of resources and patients' need to access treatment quickly, particularly when children were unwell:

> Florin: I really don't want to speculate – it's still really complicated…because, I understand – but on the other hand, they say that it's too many immigrants, and then they just - so you can't see any solution, so -I don't know – what I think always think, because some people get over – they overreact when their children get a fever, or a runny nose or something. "Oh, let's go to the GP." I know many people like this…
>
> Florin: I always try to tell them, "Go and see a pharmacist, give them some Calpol. Nothing's going to happen for one day – if you give them Calpol, or any, like, Paracetamol, or something like that. If it's going to work, off your hands - if not, then you go".

Although Florin thought that some appointments might be wasted, when symptoms did not signify serious illness, the difficulty Roma people experienced in judging when to visit the pharmacist and when to go to the hospital was highlighted in an alarming story concerning his own child:

> Florin: …I'm going back to the situation when my daughter had meningitis – so that's what I've done. I went to see the pharmacist, I said she had a very high fever, "Give her Paracetamol." I've given her Paracetamol, for like, three days, or four days. Nothing happened. We went to the A&E, waited there for four, five hours, they give us antibiotics, we came back home, take that for another two days, and I think -she's getting worse, so we went back to the hospital, and then they made some more checks, and realized that she's got meningitis. After that, she got treated and everything. I felt that one day longer, she couldn't be with us.

In the literature, Marsh (2017) reported differences in health and wellness experiences across provision and area in Wales, echoing the experiences of the participants in London. The FRA (2012), Fremlová (2009), and Fremlová and Ureche (2009) found Roma patients to have a perception of inadequate services. However, this sometimes resulted from a lack of knowledge of the differences between healthcare services in the UK and in the Roma patients' countries of origin. Poole and Adamson (2008) reported a perception among healthcare staff of wasted resources if appointments were not kept by Roma patients.

Comparisons with experiences of other groups of service users did not appear in the literature; nor did examples of Roma people considering the complexities of the situations described. The concepts of voice and agency, seen from a post-structuralist perspective, are used in Chapter six, to reframe the discourses underpinning some of the literature regarding Roma health and well-being in the UK.

Positive experiences of services

As well as negative experiences relating to health and well-being in London, eighteen participants reported many positive experiences. Although there was disagreement among the participants as to whether or not Roma people received better healthcare in the UK than in their countries of origin, some reported few personal negative experiences, with one perceiving UK healthcare provision as equitable for all.

Notably, maternity services and services for children were experienced as good, with participants reporting positive experiences of childbirth in London hospitals, either their own or those of family members. Agnieska's daughter, who had given birth at the age of fifteen, had been particularly well cared for, receiving supportive visits for two years, following the birth of her child. Nicolae believed that care for babies was mandatory and that monetary factors would not be considered in this case. Margaryta thought that all those who were more dependent might be given the best care:

> Margaryta: …They look after the kids, in this country they look after the children, the children have priority. I can't complain about that. Only – with adults is different, but the kids, they treat them very well.
>
> Felicity: What about older people, elderly people? When people get really old?
>
> Margaryta: I don't know, I didn't have experience of that. I don't know about them. Maybe they do…if they treat the kids good, I think they treat the older people good as well, the same.

Certainly, sometimes, this was the case. In Slovakia, Paulo's older friend would have been unable to pay for medical treatment. Paulo believed that coming to the UK had saved his friend's life:

> Paulo: …for example I have one in Slovakia, he's like, 60, really, I can say, very ill; and him know this, and if him lived in Slovakia, if he no coming UK, he was (*would be)* in the cemetery now. Believe me, it's like 100% sure you know, he's very high diabetic, and they op- they cutting him, like the fingers, you know?
>
> …But you help him. Hospitals, nurses everything like, help him like, 100% you know? Like give to him house, you know because he is homeless, working in the hospital, in [a London borough], they see the situation, they asking what he needs, he say I sleeping in my car…I'm not a job, because I can't working. Even he don't know if he can like get some benefits, you know? The doctors say…they tell him, you can get, like, disability, you have - he say no, I'm not on benefits because I working here for 7 years… I only 5 months ago I lost job, and they see the situation, it's like only 2 months…

> Paulo: They give flat, they give the disability, you know, they give everything, the doctors, they helped him too much, and every day…

Other services were also positively received. Paulo was pleased with his son's Education, Health and Care (EHC) Plan, which linked all his son's needs together. In addition, despite the cultural and language barriers to talking therapies, Samuel reported some Roma people finding these very helpful. Florin also noted that many Roma people were now receiving help from the NHS to give up smoking.

Despite the large number of complaints about GP practices, positive experiences were also reported. These included a GP carefully listening to a participant with poor English, on his arrival in the UK, and a GP who had Polish records of children's vaccinations translated, in order to give the correct boosters. One participant reported a positive experience for himself and his family with the same GP over twelve years. Another, whose initial experience had been poor, had remained with her GP practice and was now happy with a different, female, GP. In terms of continuity of care, there was some recognition of the difficulties for doctors, where patients moved frequently and, therefore, changed practices.

Thinking about Roma people and mental health, Florin described the unconventional support his mother received for her depression:

> Florin: …all I can say is about the experience with my mum. As I say her, like, um…her care thing, the specialist for her was the Polish GP. She used to go over there after she'd finished – because obviously she couldn't see her when she was working, but let's say, the surgery was working until 5 o'clock, she went over there, like ten to five, and stood there, and at 6.30, they had a chat, they had a cup of tea, and you know, that was –
>
> Felicity: And she was happy to do that?
>
> Florin: Yes. Yes, because she was nice - she was a very nice lady – she even told me, "Don't worry, your mum is OK here with me, we're having a chat, we're having a tea and everything" …but I remember she had, like, an appointment to go and see a specialist, but it didn't work. It didn't work. She said she went over there once, or twice, and she said she didn't want to go over there any more…I can't say it was bad or anything, I hadn't been there – but I think it was entirely up to her –

In terms of hospital experiences, Daniella spoke positively about being referred by her GP to a mental health specialist. She had received both conversation and medication, which she continued to take, for her depression. Accident and emergency services were also positively described by some participants. Not only did they offer a solution to cultural and language barriers to services, and quicker treatment for sick children, but participants also reported being treated well. London hospitals were described as offering good treatment, and satisfactory or good care. Hospital staff were said to have more time, and to give better explanations, than GPs. Pansela and her brother, Artur, reported good care in relation to her miscarriage, although Pansela still had anxieties about childbirth.

Marcin described his early experiences in London, where he had arrived with a history of muscular dystrophy:

> Marcin: You know, I would like to say – to share my experience, because you know, in my view, I am very happy about the experience which I have with the English government, regarding to my health conditions.
>
> Felicity: OK.
>
> Marcin: Because in my life, you know, I have suffer from CMT, which is muscular dystrophy, and since I came in this country, you know, I feel very better. My feet - from the government - was very good. I have a lot of surgery in my life, which, when I came in this country my health condition is very bad, in very bad condition, and I was no able to walk, I was no able to stand, my feet…was very twisted - and since I came in this country, like, immigrant, you know, I feel very treated well, er…[personally], from the British government-
>
> Felicity: OK –
>
> Marcin: You know, first time when I came in this country, they don't ask me about the asylum seeker, they ask me about my condition.

Marcin was satisfied with both GP and hospital care in the UK:

> Marcin: Yes, it's not bad, it's perfect, you know – this is my view.
>
> Felicity: OK.
>
> Marcin: Because, you know, why I should say that, because you know, I have –I know which condition I am when I came in this country, I know which condition I am in now. That's all of what I want to say - I am pleased.

These experiences were reflected in articles by Brown et al. (2016), and by Fremlová (2009) and Fremlová and Ureche (2009), who found positive experiences of UK healthcare services among their participants, in particular, in contrast to their experiences in their countries of origin. In relation to children's health, the positive rating of services by the participants of the present study is not reflected in the literature, which focuses on a wide range of child health issues among Roma communities in the UK (Fekete, 2015; Performance and Research Team, Sheffield City Council, 2015; European Commission, 2014b; Migration Yorkshire, 2012; European Commission, 2011; Tobi et al., 2010; TS4SE Co-operative Limited, 2009), but does not examine the experiences of Roma parents. Teenage pregnancy, recounted as a positive experience by Agnieska, was noted by Migration Yorkshire (2012) as a health concern. In the following chapter, the concepts of voice, agency and culture are used to examine differences between the literature and the experiences described by the participants.

Table 6: Theme 4 – Impact of change, and generational issues

Theme 4	Sub-themes and codes
Impact of change, and generational issues	**Impact of change on health and well-being** Difficulties adjusting to life in new country, belief that Roma people were longer lived in the past, belief that the environment and food were better in the past, impact of change on Roma children, greater diversity in UK means less prejudice, benefits of broader cultural understanding, benefits of access to professional services **Issues affecting young Roma people** Identity issues among young Roma people, frustration with Roma people themselves, idealisation of the past, anxiety about the future **Issues affecting older Roma people** Difficulties in dealing with change, loss of extended family support, short life expectancy for some, communication difficulties, lack of confidence, Roma cultural taboos creating barriers, bureaucratic barriers, use of traditional remedies

The experiences described by the participants were framed within the context of migration to a new country. Throughout the interview conversations, participants spoke of the outcomes of changes in lifestyle on their health and well-being, and on that of other Roma people. Participants reported different issues facing the different generations. In addition to the overall impact of change, both positive and negative, on the health and well-being of all Roma people living in London, particular issues emerged in relation to young and older Roma people.

Impact of change on health and well-being

Some participants strongly believed that Roma people's health had been better in the past. Participants also reported Roma people experiencing difficulties in adjusting to life in a new country, which impacted on their health and well-being. However, the benefits of life in a more diverse community, and of access to professional services, were also noted.

As described by Samuel in relation to material issues, for some Roma people living in London there was a belief that the health of their communities had worsened in recent times. This was linked to the enforced change to a settled lifestyle experienced in Central and Eastern Europe in the 1960s, as well as to more recent migration to Western European countries, including the UK. Samuel and his Roma clients felt that, although there were more healthcare services, all people, including Roma people, were now more unwell.

Other factors linked to change, and reported by participants, including a busier lifestyle, the consumption of poor quality 'junk' and modified food, a lack of exercise, problems with housing and money, and a wider environment of prejudice and discrimination, led to stress and depression and a negative impact on health and well-being. Agata also spoke about the effects of a modern lifestyle on the health and well-being of children:

> Agata: Life is changed. Like I said before – the parents making more time for the children. Now, the children live in towns and other things, so it's not, er …
>
> Felicity: Find a different way to say it…
>
> Agata: …like, before, family, be very much together, now, everybody lives on own –
>
> Felicity: They're living on their own, in different places –
>
> Agata: Yes – so the parents are busy, the children looking at TV, or maybe phones, maybe laptops, something like this, so the children are too much nervous, it's not like before…
>
> Felicity: and you think it has changed –
>
> Agata: -yes – the parents going to the park, making something together, doing things together, so…
>
> Felicity: So, do you think that has an effect on children's health?
>
> Agata: Yes. Yes.
>
> Felicity: What do you think it does to them?
>
> Agata: Yes, it's too much nervous, kids not like before –
>
> Felicity: They're not so relaxed?
>
> Agata: Not relaxed – I think it's going to their health, after this, maybe this depression, something like this – the kid is not open, no talk with parents, they got everything *in* –

Also, in relation to children's health, Artur described the serious dental problems faced by his five-year-old sibling, as a result of eating too many sweets. Debora spoke about young Roma people taking drugs. She believed that a gap in experience between the generations led to this becoming a big problem for the Roma community:

> Katarina: She said that the problem it's very big especially among older people, because they have no idea about drugs at all - even she said that it was, kind of, meetings in [the charity] one day, they were showing drugs, and what it actually is, so she didn't know before. And someone, an old person, when they saw it, he said, "Oh, I think I saw it before." And they found out that a cousin, or someone from the family, had a problem with drugs. But they are not informed…

> Katarina: …and they can do whatever they want, because older people, older generation, they have no idea what there is…so… even if they see, they don't know.
>
> Felicity: They don't know what they're doing, they don't understand it…
>
> Katarina: They don't know…

Both Agata and Samuel noted that health and well-being problems linked to a modern lifestyle were experienced by others, and not just by Roma people. However, participants also reported Roma people feeling that they could not cope in their new country and experiencing loneliness and uncertainty about the future. Difficulties experienced in adjusting to a new life led to negative outcomes for Roma people's health and well-being. These included the impact of too much work, together with domestic and family-related tasks, communication difficulties, and the problems involved in attempting to adhere to Roma cultural requirements within the structures of the health service in London. Agnieska suggested that smoking among Roma people was worse in the UK because of the problems they faced, particularly in relation to stress caused by difficulties with communication.

For some participants, modern medicine was not always seen as preferable. For Margaryta, as a child, there had been no choice of medicine, but her children rejected traditional treatments:

> Margaryta: …But before we go to see the doctor, we try our own…
>
> Felicity: OK. And do you think people were healthier that way, than they are now, or here, or do you think it's the same…?
>
> Margaryta: I don't know, but it's maybe healthier, you know? I try to do it as well, before I go to see the doctor. But they don't want – "I don't like this; I don't like that". They don't want. When we was kids, we didn't have choice - you don't want. You need to, because otherwise in our country, you don't have this flavour syrup, like Paracetamol. It's bitter, and you then drink, very not nice.

It was not always easy for participants to adapt to different ways of treating illness. Margaryta reported an experience in a London hospital:

> Margaryta: - you are allowed to buy. If you go to chemist, you can buy.
>
> Yes, and you rub on the skin, for the temperature. In case you don't have that, you can use normal spirit, like vodka, or any very strong…
>
> Felicity: Then rub it on the skin, and –
>
> Margaryta: Yes. Yes, and bring the temperature down. Because in our country, we don't put ventilator when the children have temperature. I was shocked, when they put in hospital, because you are hot, you high fever, your body's hot, and once they put ventilator – you like, a fan, very cold, you can catch, on the chest, very bad infection. Because hot and cold. I was shocked –
>
> Felicity: But you wouldn't do that, you'd keep them warm, but put the alcohol on the skin…
>
> Margaryta: Yes. You know, like, to come down. Then you slept. Then you keep them warm, then you sweat, change that clothes, change all is wet, tee-shirt and all the clothes, you change for your child, or adult, put on the dry – that's it. But not this –

> Felicity: Not the fan –
>
> Margaryta: No fan. No fan. Because already your body hot, so this cold and heat, you don’t make it better, you going to make it worse. I don’t know, maybe this is new, they find it’s good, but this is how we learn back home.

Despite the difficulties associated with migration and change, positive experiences were also reported. Marcin spoke of the impossibility, in the past, of Roma people receiving adequate healthcare in Romania. Childbirth in Romania, for many Roma women and babies, had been very hazardous and, often, there was no treatment for sick or injured children or adults. In contrast, three participants believed that Roma people had better opportunities in London, including access to professional healthcare services.

Four participants also described the benefits of life in a culturally diverse city, and of broader cultural and linguistic understanding. Samuel, who had spoken about the advantages of living in London, where Roma people were less visible than they were in Poland, talked about his own experience:

> Samuel: …so I was just spending a year and a half in the UK and ended up getting used to it. I know it’s not long, a year and a half, but I went back to Poland, and (*hesitates…)* d’you know, I grew up in Poland, and when you grow up with something, in a country or in a culture, you take everything for granted, and you may think that everywhere is the same... So, when I came to the UK, I experienced something new, and I’ve seen that people are more tolerant, more open-minded, like there are many cultures, and suddenly I can blend in...

> Samuel: So, then I went back to Poland, and, like, I felt it. I felt it, like, I felt the difference. And I been there three years, and I found it difficult to adjust, to Poland, once more… And, at some point, I just decided just to come back, because I knew…I’ll be better off here.
>
> F: OK. So just that time changed you, really…
>
> S: It really has, it really has…

Two participants spoke of the importance of respect between people of all cultures and religions and described supportive relationships with friends from other cultures, with Paulo recognising similarities between Roma culture, and Pakistani, Indian, and Bangladeshi cultures. Agnieska noted the ease and speed with which Roma children learnt English, in contrast to the difficulties experienced by many older Roma people. Noting the commonalities between the different Roma dialects, Margaryta summed up her experience in London:

> Margaryta: …most of the Roma language is similar. They understand each other. Doesn't matter if is from Romania or Kosovo, or Bosnia, or Polish, we understand…

> Margaryta: …even if – Bulgaria Roma, I understand. Because I'm a market trader, so I have these people coming to me –different – Turkish, different people coming, and then, I'm trying my best…so I'm picking up from them –
>
> Margaryta: yes, I'm picking up from them. I'm multi-cultural!
>
> Felicity: Yes – multi-lingual –
>
> Margaryta: Yes! I like everything. I don't mind which people they are, which country you are, and what you believe. If your heart is good, I don't mind. You can be Muslim, you can be Chinese, you can be anything, but if your heart is clean and good, they are all people the same blood. So, it's good!

Although much of the literature looking at the health and well-being of Roma people in the UK located this within the context of migration from Central and Eastern Europe (Brown et al., 2016; Willis, 2016; Performance and Research Team, Sheffield City Council, 2015; Clark, 2014; McNulty, 2014; Migration Yorkshire, 2012; RSG, 2012, 2010; Tobi et al., 2010; Poole and Adamson, 2008), there was limited focus on Roma people's experience of change linked to migration, or on the experiences they shared with other groups. McNulty (2014) and Tobi et al. (2010) did link the experiences of their Roma participants with those of other newly arrived and Eastern European migrant communities, and Clark (2014) noted the importance of inter-cultural exchanges in avoiding stigmatising narratives about Roma people.

Nevertheless, the literature as a whole seemed to separate Roma people in the UK from other immigrant communities, whereas the responses of the participants of the present study suggested a greater sense of this shared experience. In Chapter six, the participants' use of processes of identification with non-Roma people in order to reposition themselves in relation to marginalising discourses is noted using the concepts of identity and agency viewed through the lens of post-structuralism. Concepts of culture and nomadism, problematised by post-structural thinking, are also used to examine the overall positioning of Roma people in the UK, in relation to the experiences of migration to a new country.

Issues affecting young Roma people

Particular difficulties, in relation to change, were reported by the younger Roma participants. None of the participants had been born in London, or other parts of the UK. However, Pansela and Artur, who had spent their childhoods in London, seemed to experience a cultural struggle that others, who had grown up in CEE countries, did not. Artur described difficulties in his relationship with other Roma people. When asked if there were differences in approach to health and well-being between Roma and British cultures, Artur distanced himself from Roma culture:

> Artur: … To be honest, I've not experienced the Roma, you know, like, the *Roma*…
>
> you know, I'm like, I'm more into England, I know more about England than I know about Roma, so…

During the interview, Artur referred to issues in relation to gender, with which he was struggling. Stephanie, his representative during the interview, developed the conversation:

> Stephanie: What about your family on your father's side? Are they more traditional Roma?
>
> Artur: Yeah. Really, really traditional…

> Stephanie: OK, so, do you think that you could talk openly about health matters with your father's side of the family? Because you talk quite openly together here…
>
> Artur: No, I have my father's sister, that I'm only close with her, but, none of them – but she's only twenty, so –she's young, I don't think she knows - and plus she doesn't even know how to read or talk in English…
>
> Felicity: OK…
>
> Stephanie: So, do you think that there would be things that you wouldn't talk about in front of other members of the family, or things that you might…
>
> Artur: Yeah, I wouldn't talk about a lot of things…

Artur's half-sister, Pansela, believed that English people received better healthcare than she did, because she was a Gypsy. In relation to this, she described her experience on the streets in London and the impact of this on her sense of identity:

> Felicity: Do you think some people think that – do you think some people have a problem with Gypsy people?
>
> Pansela: Not some. *Everybody*.
>
> Felicity: Everybody?
>
> Pansela: Yes.

> Felicity: That's a big thing to say. Why do you think that would be?
>
> Pansela: Because sometimes, even if you try and ask for the time, or something, outside, they will try and run away, and say "No, sorry, I'm…" and I'm feeling scared as *well*! What's going on? I don't know what's happening!
>
> Felicity: And you're just going to ask for the time…yes…
>
> Pansela: You just ask them *anything* and they will be scared of you. Like, I've got a gun or something (*laughs*)

> Felicity: Right…well, what do you think they're thinking?
>
> Pansela: That we're going to rob them or try to hit them…

Pansela agreed that people were responding to a stereotype, but she thought that, in some cases, it was true:

> Felicity: ... How does that make you feel?
>
> Pansela: Feel not be proud to be Gypsy. I don't really like Gypsies.
>
> Felicity: Does it make it difficult for you…
>
> Pansela: - very -
>
> Felicity: - to feel comfortable being a Gypsy.
>
> Pansela: Very.

Pansela and Artur both expressed frustration with Roma people themselves, particularly in relation to the raising of children. The participants reported young Roma children smoking, taking and selling drugs, and drinking alcohol. Artur and Pansela, in separate interviews, communicated discomfort and criticism when speaking about Roma parents' ways of dealing with these issues. Both Artur and Pansela were also critical of Roma people's approach to working, and to improving their lives. When speaking about Roma people and stress, although she knew that money worries and poverty led to stress, Pansela seemed exasperated by Roma parents' approach to their children:

> Pansela: No, I don't think - they always just talk about money. The thing is, they don't care about their children, they care about the money. That's what they're stressed about. It's their *money*.
>
> Felicity: Right. And they're not worried about their children?
>
> Pansela: If they *did* worry, their children would be going to school. But now these days – it's not even now these days – a long time back as well, little kids, like even my cousins, they take drugs. They sell drugs. They drink alcohol.

> Felicity: And do the parents know?
>
> Pansela: The parents know, they do get angry sometimes, but they don't really – they don't know how to *talk* to kids. They don't know how to.

In contrast to his experiences of the UK, Artur seemed to idealise Poland, the country of his birth, which he had left at the age of two:

> Artur: In other countries? Oh my God, I love Poland! Poland, doctors, the hospital, I love it! I really do.
>
> Felicity: Why is that? Why do you like them?
>
> Artur: It's because I was there, ill, and sick, I had so many troubles, and they just healed me in no time. I did not have no complaints.
>
> Felicity: How did they do that?
>
> Artur: I don't know. That's the thing. It's so different from here…

Pansela, on the other hand, who was Polish but had been born in Germany, and had been in the UK since the age of three, viewed Poland in a negative light. She described it as a place of poverty without support for the poor. Pansela was pregnant at the time of the interview. She lived with her English boyfriend and had positive plans for the future of her family. Artur, however, seemed more troubled by his difficulties. He reported having briefly attended counselling through a referral from his school but had not found this to be useful. Artur was supported better by his representative, who worked with him professionally, although not as a healthcare worker:

> Artur: Yeah but, she was talking to me about my gender, everything…it was nothing. She was just talking, advising… like, I have *you* [Stephanie] to advise me, so why do I need anybody else?
>
> Felicity: Is it easier to talk to Stephanie because you know her better?
>
> Artur: Yeah. I know her for so many years, that's the thing.

> Felicity: Yes. OK. So, talking about it over a long period of time, with someone that you trust, *can* be helpful.
>
> Artur: Yes.

Unlike his half-sister, and echoing the views of some of the older participants, Artur, the youngest in the cohort, had a less than positive view of the future:

> Artur: They create too many things and it's just – I don't think these machines are positive nowadays – yeah, I don't think it's positive nowadays, it's just a machine that –
>
> Felicity: What would be better, then…?
>
> Artur: I really don't know… (*little laugh*) I don't know - everything is changing, these years, everything is changing…it feels like very soon, in a few years, it's going to be like, this world, this earth, is going to be, like the cars are going to fly –or something like…
>
> Felicity: ok…
>
> Artur: Alien planes – I don't know…

As described in relation to emotional difficulties, Margaryta's teenage daughter, who had been born in London, found her schoolwork stressful. Nicolae noted that, in Romania, Roma girls were not sent to school. Lavinia, however, recounted a different experience for her daughter:

> Felicity: And your daughter's in school…
>
> Lavinia: Yeah (*laughs*), my daughter…
>
> Felicity: Has she been in school in England for six years then?
>
> Lavinia: Yes, in year 3, I think…
>
> Felicity: Yes, OK - so she speaks very good English…
>
> Lavinia: Oh yeah, it's –from 300, then, she's the third…
>
> Felicity: Oh wow…brilliant

> Lavinia: Yes…she wants to be a doctor paediatre.

Although the participant cohort of the present study was not large enough for generalisations to be made, the interview data suggested particular difficulties may be experienced by young Roma people born in London and the wider UK. Margaryta spoke poignantly about the effect of cultural change on identity:

> Felicity: So, your strategy is not to let people know?
>
> Margaryta: Yes. My daughter does same. She doesn't tell them at school. She says, "Don't tell, Mum, please don't tell." My older daughter, my son, say please –
>
> Felicity: They think of you as Bosnian, but not as –
>
> Margaryta: Yes, because they're born here, they think they're British.
>
> Felicity: Yes, ok. You know, they *are* British.
>
> Margaryta: So, for them, it's no different. They don't mind, because they think they're British…. they speak very good English, they're educated from the beginning, so, for them, is no bad…

> Margaryta: I say to them, one day you going to make – (*in a soft voice…)* don't forget who you are. You're born in this country, but you have this Gypsy blood inside you. I say, don't forget who you are. "We are British, we are British." I say yes. I'm not. You are. But you are my daughter, you are my daughter. Don't forget that. [5]

In terms of intersectionality, younger Roma people, born or brought up in the UK, appeared vulnerable to experiencing dissonance between Roma and British culture, resulting in complex location of identity whilst, at the same time having greater ability to negotiate life in the UK than their older relatives. The literature on Roma health and well-being in the UK

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[5] Margaryta's heartfelt plea, and the ambivalence expressed by Artur and Pansela towards Roma culture, reflected the issues, such as changing family structure for Roma people in the UK, and current identity confusion for many Gypsies, Roma and Travellers, discussed at the Advisory Council for the Education of Romany and other Travellers (ACERT) conference on identity in London in September 2016.

did not specifically examine the experiences of young Roma people. Although there is a wide generic literature on the experience of migration to the UK, including inter-generational experiences, the experiences of young Roma people do not appear to be included in this focus, either within the wider literature or among studies looking at Roma health and well-being in the UK. Issues regarding identity and agency, in relation to migration, including those affecting young Roma people, are discussed in Chapter six.

Issues affecting older Roma people

In addition, thirteen participants, across the age range and from four countries, described specific issues affecting older Roma people. Differing views were expressed, as to whether older Roma people received better or poor support for their health and well-being in London. However, the degree of adaptation to a new healthcare system that was required seemed greatest for older members of the Roma communities. It was not clear how many older Roma people were living in London, or how participants defined the term 'older', although Debora suggested older people would be aged fifty or more. Florin thought that older Roma people had adapted to modern medicine, but others described many problems. Sabrina and Paulo spoke of the difficulties for older Roma people in dealing with change:

> Paulo: The old people are always complaining, you know? If they come back from the doctor, he's like no good, he make their own I take *this*, you do *this*, you know. I ask him for this medicine, he give me something different, the change is too much, you know. For example, my mother, always she complains, you know.

Participants described differing degrees of access to healthcare services in their countries of origin. Kristina, who was her mother's main, full-time carer, reported that her mother's family had access to doctors and hospitals in Poland. However, other older members of the communities brought with them a history of disadvantage and poor health outcomes. Participants spoke of grandparents who had died from untreated diseases, when specialist medical care had been unobtainable, and of the poor life expectancy of members of some Roma groups:

> Marcin: My family, they didn't have a long life, they reach maybe 60, 65, it's lucky for reach 65.
>
> Felicity: And that is Romanian Roma? Roma generally…?
>
> Marcin: No, just, you know, a few groups of Roma…some of them, they are living quite a long time 70, 80, 90…
>
> Felicity: Why do you think that might be?
>
> Marcin: I don't know, it's difficult for me to say why. This what we describe. All of us. My father died 50…my mother died 65, my brother died 38, and my other brother 40, 50, uncles too. All my uncles they died less than 60.

Marcin was uncertain of the reasons for this short life expectancy, thinking both genetic and lifestyle factors might be involved. Samuel, and his Roma clients, believed worsening longevity to be firmly linked to a more modern lifestyle, poor diet and lack of exercise. For Agata, the use of antibiotics, whilst sometimes necessary, was related to an increase in serious illness, which she linked to increased stress and unhealthy food. The healthcare received by Marcin in London was significantly better than the healthcare that was available to him in Romania. However, some older Roma people in London appeared to be trying to adapt to a lifestyle many of them perceived as contributing to poor health outcomes.

In terms of treatment for health issues used by previous generations, participants described the use of traditional remedies. Marcin acknowledged the use of home remedies in the past but noted that, on occasion, there had been no treatment at all for injuries or pain. Some participants thought that, while traditional remedies and advice could be helpful, modern medicine, as well as professional support for mental health problems, were sometimes needed. Despite these reservations, traditional medicines were said to still be preferred by some older Roma people and were generally reported to be effective. Participants described the use of lemon drinks for asthma; onion and sugar, beetroot, and honey and lemon for coughs; teas for headache; an alcohol and potato mixture for a sore throat; cabbage leaves for wounds; and herbal soup for rheumatism. Florin described his grandparents' view of doctors and modern medicine:

> Florin: … I remember that ages ago, older people –like my granddad and my grandma, they used to – didn't like doctors…I think that was everywhere to be honest. They didn't like them, they used to do the home remedies, they used home remedies, like you know, many things, they used honey and things like that…
>
> Felicity: What sort of things did they have?
>
> Florin: And they – I remember my grandmother would do, like, mmmm, I can't remember…she would, like, honey, and lemon drinks, something like that – we didn't have to go to see the doctors, tablets, they're really bad for your body, they're only chemical weapons! I remember, she always used to say that – I'll treat you at home, don't worry…

Participants reported a convergence of difficulties for older Roma people in adjusting to life in a new country. As described by Agata, in relation to cultural issues, a more demanding lifestyle left some older Roma people in London without the traditional level of extended family support. In addition to a potential negative impact on their physical health, participants reported older community members struggling with difficulties preventing successful access to healthcare services. These included language problems and a lack of knowledge about UK health services, and an associated lack of confidence and fear. Roma cultural taboos added to the problems faced by older community members, particularly in relation to accessing mental health services. Three participants, Paulo, Sabrina and Nicolae also reported specific difficulties facing older Roma people who wished to register with a GP. Samuel described the problems faced by older Roma people in overcrowded hospitals in London:

> Samuel: I haven't come across a lot of older Roma people. I think it's a struggle, because usually they don't speak English, and…well, I just been to a hospital, and I saw the difference between Polish hospitals and English hospitals. And they are really crowded here. And I saw a lady, a non-Roma lady, approaching a nurse, crying, and saying that she was told that she would have scans a few hours ago, and she would be given medicines, and she was still waiting, she was in pain, and no one came up to see her, and she was very upset. And I think those things are not happening in Poland. Not much. And she was an older lady. So, I do not want to judge the whole health system in the UK, but

> this is the experience I have had. And there is the other experience of my aunt, who is reaching her sixties, and she is waiting for the operation for two years. I think she also would wait a long time in Poland, but maybe because they are able to speak for themselves, they do not need interpreters, it's much easier and faster for them.

These difficulties were said by four participants, Daniella, Nicolae, Sabrina and Paulo, to result in older Roma people staying at home, rather than engaging with healthcare services. It was said to be common for elderly Roma people never to visit doctors or dentists because they were afraid. Roma cultural taboos regarding mental health added to these difficulties. Dana spoke about her mother, who had been going to psychotherapy in Slovakia but was afraid to go to doctors in the UK. Dana's mother sounded very unwell, mentally, but could not get the help she needed because of her fear. Her mother suffered from hallucinations and the fear was part of her illness but, also, she feared being laughed at for being ill. Dana noted that elderly Roma people do not like to talk about their problems because of the taboo against this, and the resulting cultural fear of humiliation. Viewed intersectionally, older Roma women were more likely to report difficulties with the English language and with interpreters which, together with the cultural prohibitions regarding Roma women's health and the reported problems facing many older Roma migrants, produced a positioning of great difficulty.

Bureaucratic barriers also faced older Roma people seeking healthcare in London. Nicolae described the situation facing an elderly member of his family:

> Nicolae: …I can give an example of one of my cousins, he's got his grandmother here, and she's seventy-something. She's not able to speak even good Romanian. All her life – all her life she was speaking Romanes. And um, he tried to get her registered with a GP, and he's been trying I think for the last two months, because they keep asking her to provide bills, all sorts of things that she's not able to provide, because she's – she came three months ago here, she's obviously not able to work, or something, so she can provide a proper income or something, pay slips or whatever. And, you know, because she was left alone in Romania, they decided that it was better for her to live here, with him, so it's – it makes a lot of – it makes all the sense that she has to be registered with a GP, just in

case she needs something, considering her age, and he finds it very difficult to get her registered with a GP.

The views of the participants, regarding poor life expectancy among some Roma groups, were echoed within the literature, with many studies quoting a significant deficit among Roma people generally (National Roma Network, 2017; Performance and Research Team, Sheffield City Council, 2015; FRA, 2012; Migration Yorkshire, 2012; European Commission, 2011; Tobi et al., 2010; Hajioff and McKee, 2000). However, this was based on estimates, rather than on statistical data, with Braham (1993), the source of an often-cited ten-year deficit, also reporting many older people among the Roma. The importance of research evidence in support of assertions regarding Roma health and well-being, in order to avoid the creation of narratives that obscure diversity within Roma experience, is clear.

Within the existing literature, Hancock (2002) and Acton et al. (1997) discuss the use of traditional herbal medicine, although the focus of other articles is on modern medicine. Sheffield City Council (Performance and Research Team, Sheffield City Council, 2015) mentions cultural issues relating to healthcare and homeopathy among a list of problems identified by healthcare professionals, in relation to local Slovak Roma communities, thereby privileging the biomedical model. As with young Roma people, the specific experiences and needs of older Roma people in the UK, in relation to their health and well-being, were not a focus of the literature. In Chapter six, post-structuralist concepts of voice, culture and nomadism are used to problematise the relationships between the literature and the findings of the present study.

Table 7: Theme 5 – Factors enabling improved health and well-being

Theme 5	**Sub-themes and codes**
Factors enabling improved health and well-being	**Structural support** Benefits of free healthcare, NGO support, Roma mental health project, greater focus in UK on child development, leading to referrals from school or GP to specialists for special educational needs and disability, enforcement of school attendance in UK leads to support for children with special educational needs and disability **Education and rights** Learning English, obtaining right to remain or citizenship, training for healthcare staff, education for Roma people about health and well-being, need for positive measures to be mandatory, importance of children learning English, valuing

	education for children, positive ambitions of young people, obtaining higher education, obtaining work supporting Roma people **Preventative approach** Preventative approach to health and well-being, poor take-up of health checks and preventative measures, taking responsibility **Mothers** Intergenerational knowledge of mothers about healthcare Importance of grandmothers' care

During the interviews, participants also referred to factors that enabled improved health and well-being outcomes for Roma people in London. These were grouped under four sub-themes: structural support, education and rights, a preventative approach, and the importance of mothers.

Structural support

In terms of structural support, four participants stressed the benefits of free healthcare, contrasting this with the high cost of medical care in their countries of origin. Marcin recalled the impossibility for Roma people of obtaining adequate healthcare in Romania, where payment was required. Although he had tried to pay, he had not received good treatment for his muscular dystrophy in his home country. Pansela was unsure as to why healthcare was free in London but saw this as very beneficial. She described the UK as the best country for a Roma person to live in. Lavinia described a lack of medical equipment in Romania, and the need to pay tips to augment the low basic salaries of Romanian doctors. She spoke of her initial surprise at not having to pay in London:

> Lavinia: When I come here, when I was first time here at surgery and er, I saw how beautiful, how nice - they speak with me, care about me, you know? (*laughing)* I call my husband, "Bring me money to give to the nurse" ...because I was usually in my country…but here it's not …the doctors and nurses is very nice, to care for…
>
> Felicity: OK…so you were surprised by that?
>
> Lavinia: Yes, of course – the first time I was seeing, yes…(*laughs*).

The importance of NGO support for Roma people in London was also noted by six participants. Those who were involved with the charity supporting Roma people, as clients or as members of staff, spoke of its benefits. Four participants mentioned the charity's mental health project, specifically devised for Roma clients. Sisters, Margaryta and Elise, had differing views about the potential effectiveness of the project for Roma people, with Elise thinking it would take time for them to be able to benefit from it. However, after discussion with her sister, Elise recognised the practical advantages of the project:

> Elise: [The charity], they have help…and they helping the people…they book appointments, they go with you, or, if you struggle to call people like these, sometimes they thinking very well, sometimes, because they not well, can't think properly, so they doing it, they call, they represent you, just give your name, and after, they talk in your name, and sort out the problem, so it's not going to become worse. So, this project is very, very good.

Debora and Nicolae spoke of the importance of the information offered to Roma clients by the mental health project and believed it to be making a huge and positive difference. Dedicated support for members of Roma communities in London was very limited. Agata thought there should be more places like the charity, as those who could not speak English were unable to access support through other agencies, such as Citizens Advice, where interpreters were not provided.

A greater focus on child development in the UK than in their countries of origin, and support for Special Educational Needs and Disability (SEND), were seen by three participants as contributing to improved health and well-being outcomes for Roma children in London. Sabrina and Paulo described the identification of their son's learning difficulties by their GP, following which he was given specialist support, including language therapy. Despite a lengthy and complex process, their son had been given an EHC Plan, which identified all his needs and support in one document, and which they found helpful. Samuel spoke of much faster referrals of Roma children in mainstream schools in London:

> Samuel: ... I think here in the UK, they are focusing on children and their development. So, I know about children who are five or six years old, or seven years old. And they go to all sorts of specialists. They may have been referred through school, or via GPs. There

> are a lot of therapies, speech and language therapies. If someone thinks the child might be autistic, or might have any delays, it's much faster than in Poland. They go to mainstream school, and usually no-one notices.

Samuel connected this to a greater enforcement of school attendance in the UK:

> Felicity: ... Do you want to say anything about what would happen if they – if you had an autistic child in Poland, for example? A Roma person had a -
>
> Samuel: Probably they wouldn't be aware of that – as soon as they could be over here - there is a reason why. They have to send kids to school in the UK. They have to send kids in Poland also to school, but it's not that strict. Once the teachers or head teachers see that this is a Roma child, they kind of do not care about their attendance. And here it's completely different. So, once we are at school and the professional notices something, they may speak to the parents, and they may refer the child to a specialist.

Although secondary school examinations were a source of stress for some young Roma people, the UK school experience in general was reported as positive:

> Nicolae: …and what I want to say is also possible, is that people have a very good opinion about school in the UK, and whoever I talk with about their kids having problems, of being treated differently, in schools – no-one. So far to me personally, no-one's said that their kids suffer because they are being treated differently at schools. Which I think is encouraging people to come here as well… [6]

In the literature, a range of strategies for promoting improved access to services were identified. These included the active participation of Roma people (Marsh, 2017; Brown et al., 2016; Willis, 2016; RSG, 2012), but there was little focus on Roma people's own views

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[6] Nicolae's comment was interesting, as many problems were reported for Roma children and families in UK schools, in a presentation given by the charity at the National Roma Network Forum in Salford in April 2016. The parents' views reported by Nicolae might be seen within the context of better school experiences in London than those they had in their countries of origin.

about factors enabling improved health and well-being. The benefits of existing structural support were not explored in the literature, although the RSG reported positive feedback from all service users of their Mental Health Advocacy Project (RSG, 2012). In Chapter six, processes of adaptation by Roma people to living in a new country are explored, using the concepts of agency, identity and culture from a post-structuralist stance.

Education and rights

Four participants stressed the significance of education in enabling improved health and well-being experiences and outcomes for all Roma people in London, and the value of education for children and young people was strongly emphasised within the interviews. Participants spoke of the need for children to learn English, as well as the languages of their countries of origin and the Romani language, and of the importance of sending children to school:

> Pansela: … I just want to live for my kids.
>
> Felicity: You want to be healthy so you can look after your children well, have healthy children.
>
> Pansela: Yes. Yes. I want them to be smart, healthy, and obviously to go to school. The most important thing.

Obtaining further and higher education also offered positive benefits to the health and well-being of Roma adults living in London. The two participants who had received education at these levels in their countries of origin had not only benefitted personally but had been able to find work supporting other Roma people. One participant had learnt some English at school in his home country, and this had facilitated a smoother experience of migration. Another spoke of the way in which obtaining higher education had opened his mind. [7] Agnieska suggested that the experience of healthcare services in London could be improved

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[7] At the Advisory Council for the Education of Romany and other Travellers' (ACERT) conference on identity, held in London in September 2016, a number of presentations were testament to the emergence of an educated class among the Gypsy, Roma and Traveller collectivity. An increasing number of Gypsy, Roma and Traveller people are determining their own identities, and benefitting from further and higher education, and not everyone is poor.

for Roma people through better provision of interpreters and more accessible English language classes.

Samuel spoke of the need for education for Roma people about health and well-being, alongside training for healthcare staff. The education and training provided by the charity for both clients and local healthcare staff was said to be very helpful. One participant described taking part in the production of leaflets to inform health professionals of the best ways to work with Roma people.

However, the participants suggested that more needed to be done. Nicolae spoke of the need for advocates to bridge the cultural gap between healthcare professionals in London and Roma people. He felt that Roma health mediators could be helpful in the UK and stressed the need for positive measures to be mandatory. Debora believed that doctors in the UK treated patients from other cultures with respect but, because they were not informed about Roma culture, they did not recognise it. Samuel described both the difficulties and the benefits of providing training:

> Samuel: I think the professionals, the health services, that would be ideal, if they would be aware who the Roma are, what is their culture, what previous experience have they had, in the countries of origin. I think it would be very difficult to do it, because we have so many cultures and you cannot expect every single GP or a nurse, to know everything about every single culture. You may have Somali, you may have Ethiopian, Asian, but we've run some trainings to help professionals, and I think we were successful, and we had a good feedback. And some of the professionals we met were saying that, "Thank you for sharing the knowledge, because now I see that in the past I could have done something wrong." So that would be helpful. If we, or someone else, could deliver training sessions and the professionals would be more aware about Roma cultures.
>
> Felicity: OK. So, a lot of the problems are because people just don't know.
>
> Samuel: I think so. [8]

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[8] Feedback collected by the present researcher during voluntary work for the charity supported Samuel's comments. Health professionals reported increased understanding and awareness of Roma culture, and of the barriers facing Roma patients (Smolinska-Poffley and Zawacki, 2017).

The participants also raised factors in relation to their rights. Two participants reported several occasions where, despite being aware of their entitlement to do so, they did not take up the opportunity to make a complaint about poor quality services and treatment. It was unclear as to why this was so. Kristina stressed the necessity of continuing to ask questions of the healthcare staff, until she clearly understood the information.

Gaining British citizenship did not offer participants protection from all the difficulties they faced in London. Nevertheless, Marcin, who had received good healthcare treatment since his arrival in the UK, described the benefits of obtaining citizenship for his well-being:

> Marcin: My experience, life experience was more feel, more safe, more confident, because, you know, because you know stay, stay in this country, I feel no more fear, but my health condition, you know, is just, like, the same treatment as before.

The views of the participants were reflected in the literature, in which the need for training and education for both healthcare professionals and Roma people was stressed. Several studies noted the importance of training for healthcare practitioners, to develop understanding of Roma culture and the discrimination faced by members of Roma communities (RSG, 2017; Shallice and Greason, 2017; RSG, 2015; Equality Commission for Northern Ireland, 2014; FRA, 2012; Wright, 2011). Other articles noted the need to provide education for Roma people about healthcare services in the UK, and general health and well-being education (Performance and Research Team, Sheffield City Council, 2015; The Social Marketing Gateway, 2013; RSG, 2012). However, cultural awareness training can promote discourses that trap Roma people in a perceived ‘traditional’ and unchanging culture, and which fail to work with processes of cultural change, adaptation, and cultural movement between the traditional and the modern. These issues are explored in the discussion from a post-structuralist perspective.

Preventative approach

The value of a preventative approach to health and well-being, and the need to take responsibility for this, both individually and collectively, were also identified by six participants as factors enabling improved experiences and outcomes. Kristina stressed the need to be responsible for her own understanding, and to ask the doctors to explain what they were telling her, which she believed resulted in a positive experience. Florin and Marcin described the voluntary work they, themselves, undertook, in order to help other Roma people to access health and well-being services in London. In the absence of more formal systems, this voluntary work was an important means of support for members of their communities. Paulo, who noted that many Roma people were coming to the UK to work for a better life, described taking responsibility for the problems he faced when he first arrived in London:

> Paulo: … well…because I'm come first, about two or three months? Like, before, two or three months. And I feel like, really, no good. I'm tell my sister, my brother, I'll never stay here, because what happened yes? I can't speak English, even like zero, you know. Completely zero (*laughs*) so when I want to go to the shops, can't speak English, you know? I speak Polish and these people don't understand…so I feel like, really different, you know? Because, before, I just live in Poland, I'm never moved from Poland, so it's very difficult for me, but three, maybe like six months and I'm starting like, I love this country. I don't know why, but the main thing is, when I work with Polish people and Gypsy people, Roma, it's like only Polish, Gypsy, Polish, Gypsy. No language. So, I can't like, learn English, you know? So, I'm like, change my job, I changed my people, you know? And I just go to English, or like Asian people or different…I can speak *English*, you know? And after, I feel good.

However, with regard to prevention and taking responsibility, five participants - Magdalina, Samuel, Debora, Pansela and Kristina - expressed criticism of Roma people in general. It was suggested that Roma people were not fighting for their rights and that they should try harder to communicate with healthcare staff, in order to improve their understanding. Magdalina pointed out that communication difficulties had to be addressed on both sides, but she thought that Roma people, themselves, needed to understand how and where to get the help they required. Speaking of her own struggle to stop smoking, Lavinia noted the need for self-motivation, rather than relying on other medications and treatments.

In relation to a lack of money and the resultant stress, Pansela thought that Roma mothers should take a more responsible and proactive approach:

Felicity: OK, so what you're saying – are you saying that stress –

Pansela: - makes them not think properly.

Felicity: Yes - and that's caused by lack of money…mostly…

Pansela: Yes – *and* children – when they get –when the children are making you angry…

Felicity: yes…yes, ok, so not having enough money and having a lot of children –

Pansela: Well, it's not anybody's fault, it's *theirs* because they make this much children.

Felicity: You think they've got too many children? -

Pansela: Yes. They *do* have too many children.

Felicity: And they don't have enough money –

Pansela: - they don't have money, and they'll be having next by next children. They don't really understand –

Felicity: They're not planning it –

Pansela: - planning *anything*…

Samuel, in a gentler way, also believed that Roma people could do more to prevent ill health:

Felicity: ... And is there anything Roma people could do to help themselves more, do you think?

Samuel: Um…they could look after themselves much better. So, they could go to services not when they are sick, but to prevent.

Felicity: So, more preventive –

Samuel: Usually they don't do it. Women do not go to scan their breasts. Um, they do not – I mean they check their blood pressure, it's very common, but I think they should take care of themselves much more. Go to services, available services, and just take care of themselves.

Despite these criticisms, participants were very aware of the problems facing Roma people, and of the ways in which these problems made adopting a proactive and preventative approach difficult. Both Magdalina and Nicolae noted the need for healthcare professionals to take responsibility for their interactions with Roma patients. Nicolae suggested that GPs and specialists should consciously improve their communications with Roma people, to create positive relationships. He believed that healthcare professionals had been educated in order to provide positive experiences and services for their patients, but that this did not always happen for Roma people, often as a result of prejudice.

Five participants were also very aware of the barriers created by poor educational levels. Agnieska stressed the impossibility for some, older, Roma people to learn English, as they could not read or write in the language of their country of origin. Florin noted that some Roma people found learning English relatively straightforward, but that others found it very difficult. Nevertheless, this did not mean that they did not want to speak it. Samuel, also, pointed out the problems they faced, and the need for two-way education and preventative measures:

> Samuel: … But I think they are lacking in knowledge. What is available, and what you could do for yourself. And then, again, to train Roma people is kind of difficult, because I think a lack of education. You have to put everything in very simple words. And sometimes they just do not understand.

> Samuel: … I think it's crucial – it's crucial to educate people – like both ways…um…the community, about having a mental health illness, but also in general about health – we talk about health and it's also, like, prevention, or hygiene, a healthy diet, because it has a huge impact on your whole life and, at the same time also, educating the professionals, because they should be aware about the barriers, and this is what we do.

Despite the many difficulties, there was a strong sense within participants' responses that Roma people living in London wished to improve their own health and well-being:

> Elena: …so even if they want to – have good health, they don't know how to look after themselves, you know? They don't know how to ask for – how to ask the questions.
>
> Agata: You have to – *(Polish)*
> Elena: So, they have to – interpreters - she said they have to use very simple language, to understand, but basically she said they would like to be healthy, but they don't know how. Because they don't know how to ask, where to find information, people are illiterate, they can't read and write *(Polish)* – basically the people from outside, they see Roma people, like they don't want to do something, like, to be healthy, to have good diet, but she say they don't know *how*. How to do it.

In the literature, the European Commission (2014a) report on the implementation of the EU framework for National Roma Integration Strategies noted the need for a greater emphasis within Member States on the prevention and treatment of non-communicable diseases, on general health campaigns and on the promotion of healthy lifestyles. The findings of the Social Marketing Gateway (2013) mapping report included the need for health education for Roma people in Scotland, leading to greater preventative care. The views of Roma people with regard to preventative healthcare measures did not appear in the literature. In Chapter six, issues of responsibility, and the value of including Roma people in planning preventative health and well-being strategies, are considered from the point of view of post-structuralist views of the concepts of culture, voice and agency.

Mothers

Finally, four participants stressed the importance of intergenerational knowledge about healthcare, passed from mothers to daughters. The participants noted that, in the past, Roma people did not go to doctors, and that Roma women treated illness, unless it was serious. Margaryta described the old women of her community using Paracetamol, massages and tea, as well as spirit alcohol to bring down a high temperature. Paulo and Florin both spoke of the importance to children of healthcare received from their grandmothers:

> Paulo: … I really loved my grandmother, I really loved her, she go to doctor sometimes but many times she did something different, you know, in the house…this is when I'm a child – I can't remember, but, if she coughed, she not go buy something, she make something in the house. You know, the children, like me, like my sister, even like, when I have a cough, she make something for me. And it was good, it was very good.

> Felicity: And did their remedies work?
>
> Florin: Yes, when I was a child, they *did* work. For a kid, everything from your grandmother works!

And Pansela captured the universality and timelessness of the part played by all women in caring for the health and well-being of their families:

> Pansela: Like…English people know as well, I think. It's many things because…they are actually like doctors, mothers. They're always like doctors, they used to – my Mum used to care for me all the time. Even if the doctor wasn't there, my Mum was always there.
>
> Felicity: Yeah…
>
> Pansela: The doctor actually didn't care for me; it was my mother.
>
> Felicity: ok, so you think mothers know –
>
> Pansela: - best!
>
> Felicity: - what to do. And where do they learn that from?
>
> Pansela: I don't really know. I learned from my mother –
>
> Felicity: - ok-
>
> Pansela: -my mother learned from -
>
> *(both together)* her mother…
>
> Pansela: - and it just keeps going…

The intersectional position of Roma women in relation to their health and well-being in the UK context is complex, due to cultural taboos. Access to services for older Roma women can be further restricted by a lack of education, communication difficulties and limited self-confidence. By contrast, of the six male participants of the present study, two reported having received education in their home countries, with two having been able to establish themselves as informal interpreters for their communities. One was proactively able to improve his situation through changing his job and learning English. Only one reported significant problems in relation to his health and well-being.

Whilst several female participants demonstrated personal agency in addressing their circumstances, or in their response to cultural pressures, within the cohort there was evidence of a greater struggle for the women. Nevertheless, this difficult location appeared to be tempered to some degree by the recognition by both male and female participants of the beneficial healthcare knowledge carried within their communities by Roma women.

In the literature, The Social Marketing Gateway (2013) found Roma women's health to be an area of concern, due to cultural taboos, and the National Roma Network (2017) noted difficulties facing Roma women, such as problems in accessing maternity services, domestic violence or social services involvement. Only Acton et al., (1997) questioned the traditional idea of Romani women as victims, in relation to pollution taboos, and the fundamental assumption that Romani people do not have knowledge about healthcare, diseases and symptoms. They suggested that the Romani system of washing taboos is foundational to Romani health practices. Acton (1998) challenged the idea of Romani women as disempowered by cultural taboos relating to women's bodies, and Acton et al. (1997: 176) proposed a shift in thinking to the idea of Romani women as '…effective change agents' in the development of health education policy for Romani women and men of all ages. The more recent literature strongly focused on the healthcare needs of Roma women (Hughson, 2021; EESC, 2020; FRA, 2019; UNFPA, 2019), and this was linked to the impact of poverty and exclusion on the health and well-being of Roma children (EPHA, 2020). The practical implications of challenges to traditional narratives about Roma women and healthcare are considered through the concepts of voice, culture, identity, agency and nomadism, viewed through the lens of post-structuralism, in the discussion in Chapter six.

5.4 From analysis to discussion

In Chapter five, the findings from the individual interviews were presented, with the focus being on the voices and views of the Roma participants themselves. The participants engaged with the topic with interest and enthusiasm, indicating the importance they attributed to health and well-being as an aspect of their lives, and each had a story to tell.

The semi-structured interview schedule generated wide ranging material, and the findings from the data analysis were organised under five key thematic headings: factors contributing to poor health and well-being; barriers to accessing services and treatment**;** experiences of health and well-being services; impact of change, and generational issues; and factors enabling improved health and well-being. Participants reported both positive and negative experiences in relation to their health and well-being, with many common themes being discussed. Differing experiences within and across a range of healthcare services, as well as differing views regarding some of these experiences, were expressed.

The participants identified a range of factors contributing to poor health and well-being. These included poverty, poor housing, poor diet, unhealthy lifestyles, high rates of smoking, mental health problems, and chronic and other physical health conditions. In addition, cultural prohibitions and taboos were linked to negative health and well-being outcomes, as were the effects of ongoing discrimination, negative media representation, the impact of the Brexit referendum and a lack of dedicated support. Overall, the findings within this theme echoed the content of much of the literature. More recent literature showed the ongoing impact of Brexit (RSG, 2021a, 2020; Stalford and Humphreys, 2020; Perraudin, 2018; Zawacki, 2018), together with the Covid-19 pandemic (Pollak, 2021; RSG, 2021a, 2021b; Hetherington et al., 2020; Korunovska and Jovanovic, 2020; Matache and Bhabha, 2020; Walker, 2020; Zawacki, 2020).

Many of the participants reported communication difficulties as the greatest challenge facing Roma people in London, in relation to accessing healthcare services. Educational issues were also said by the participants to be a key barrier to accessing services and treatment, although education was noted in the initial literature in relation to strategies for success, rather than as an existing barrier. In terms of cultural factors, practical difficulties, and language and communication difficulties, the literature reflected barriers identified by the participants. Although the literature focused strongly on Roma culture as a major barrier, there was some critique of this assumption within the literature itself. For the participants, whilst cultural prohibitions and taboos were clearly very significant, they also reported many other inhibiting factors.

The participants reported both positive and negative experiences of health and well-being services in London. Negative experiences included prejudice and discrimination on the part of some healthcare providers, as well as more generic dissatisfactions with GP and hospital services and the treatment offered. Issues around a perception among healthcare staff of wasted resources were also discussed. All of these aspects were reflected within the literature. In contrast, positive experiences of good practice were also reported by participants, echoing the findings of several articles examined within the literature. However, whilst participants strongly endorsed maternity services and services for children, the literature focused on a wide range of child health issues, identified from the perspective of non-Roma authors, rather than on the experiences of Roma parents themselves.

In other areas, the Roma participants highlighted issues that were not well-examined within the initial literature. These included the specific impact of change in relation to migration on the health and well-being of young and older Roma people. In addition, participants recognised common experiences among people from all migrant communities, and cultural similarities across groups. Whilst there was little focus in the earlier literature on the individual experience of Roma migration, or on the commonalities between Roma and other migrant communities, later studies included these aspects (Grill, 2012, 2017; Morell et al., 2018; Nagy, 2018; Smith, 2018).

Finally, the benefits of existing structural and infra-structural support, reported by participants, were not noted in the initial literature, other than the value of the RSG's mental health project. The need for education and training for both Roma people and healthcare professionals was raised by participants, and this was reflected in the literature, as was the value of a preventative approach to health and well-being, although Roma people's own views on this topic were not included. The knowledge about healthcare already held by members of Roma communities, particularly by women, was noted within the participant responses. However, only two articles, written some years ago, gave recognition to this valuable resource.

In Chapter five, the findings within each theme are compared with the literature on Roma health and well-being in the UK, with similarities, differences and omissions being noted. In Chapter six, the discussion, the concepts of voice, culture, identity, agency and nomadism, from a post-structuralist stance, are used to problematise the findings of the present study, the findings of the reviews of the literature, and the relationships between these. The focus of the discussion is on ways in which alternative narratives, particularly those proposed by the Roma participants of the present study, might contribute towards a reframing of some of the discourses surrounding Roma health and well- being. This study contributes towards emerging views regarding Roma representation and voice, Roma agency, and the positioning by others of Roma people as ‘vulnerable’, in relation to healthcare. New narratives, and a different way of seeing Roma people in this context, may enable new ways of engaging Roma people in London and the wider UK in caring for, and improving, their own health and well-being.

DISCUSSION

6.1 Introduction

Literature regarding the health and well-being of people from Roma communities is indicative of poor outcomes and particular difficulties. The present study set out to answer the question: **'To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?'**. In this chapter, the findings from the semi-structured individual interviews are examined in relation to the reviews of the background, context and literature. Wider discourses and narratives about the governance of Roma people in Europe, as these relate to the domain of health, are also considered. The concepts of voice, culture, identity, agency and nomadism, problematised by post-structuralism, are used to seek insight into these two sets of findings. Theoretical ideas, from within post-structuralist thinking, illustrate ways in which these concepts can provide particular readings of the findings of the present study. These readings are contrasted with those offered within the existing literature on Roma health and well-being in the UK, and discourses impacting on Roma health more widely. Through this process, the original contribution of the present study regarding the health and well-being of Roma people in London is identified and this is presented in Chapter seven.

Three key themes were found within the earlier literature, in relation to the health and well-being of Roma people in the UK: health service limitations; perception of a weak policy response; and social and cultural determinants of Roma health and well-being. The analysis of the interview material resulted in nineteen sub-themes, organised into five key themes: factors contributing to poor health and well-being; barriers to accessing services and treatment; experiences of health and well-being services; impact of change, and generational issues; and factors enabling improved health and well-being. Three significant aspects of the participants' experiences, identified throughout these five broader themes, stood out to the present researcher and these provide the focus for the discussion: processes of adaptation to living in a new country, Roma culture and their relationships with this, and their desire to speak about these experiences.

The participants reported a wide range of both positive and negative health and well-being experiences in London. Communication difficulties were widely reported as presenting a significant barrier in relation to accessing health and well-being services and, in this context, the participants communicated a strong wish to speak about their experiences. Throughout the interviews, the participants presented themselves as people building their lives in a new country, with a focus on the experience of migration. Intergenerational issues relating to migration were reported. The findings suggested a desire on the part of the participants to reposition themselves in relation to the marginalised status of Roma culture, and to represent themselves more positively. Their responses suggested that they saw themselves as less different from others than many popular discourses about the Roma would imply. This includes discourses around Roma health and well-being. The participants used processes of identification with members of non-Roma groups to reposition themselves in relation to prejudice and marginalisation. The findings indicated that questions of identity and identification were highly significant to the health and well-being experiences of the participants. The participants communicated the use of agency, responsibility and strategy for understanding and improving their health and well-being experiences, and they reported Roma people taking responsibility for their own health and well-being.

The participants reported a range of positionings vis-à-vis Roma culture, alongside a collective experience of traditional Roma cultural taboos relating to health and well-being. The findings of the present study suggested Roma culture to be changing and adapting, in relation to health and well-being. In addition, cultural judgements were found to be reciprocal. The participants described the negative impact of prejudice and discrimination on Roma mental health, together with processes of adaptation to the use of mental health services and therapies. The findings of the present study suggested that Roma women, particularly older Roma women, faced more barriers in relation to their health and well-being than were experienced by Roma men. Alongside this, participants identified Roma women, especially older Roma women, as a key source of knowledge about health.

In Chapter three, the rationale for using post-structuralist theoretical concepts within the present study was outlined. The concepts of voice, culture, identity, agency and nomadism were chosen, as each has direct relevance to narratives about, and representations of, Roma people. The present study has a particular interest in the ways in which Roma people have been represented by non-Roma people, and in their self-representation, and how these impact on their health and well-being experiences, and in the presence or absence of Roma people's voices and views in studies relating to their health and well-being in the UK.

Post-structuralist thinking posits language as the carrier of discourse, meaning as created within discourse, and discourse as the only source of shared social meaning accessible to human beings. In this tradition, language and meaning are, however, unstable, contingent and constantly prone to challenge by the trace of their opposites (Derrida, 1976). Foucault (1977), conceptualised discourse as connected to power, and power as always related to specific constructions of 'knowledge'. Whilst not identifying himself with post-structuralism, the work of Foucault has come to be viewed within the same stream of thinking as that of Derrida and others within this shared ontological view (Gutting, 2005). Far from traditional western philosophical understandings of meaning as foundational, fixed and objectively 'true', albeit distanced from human subjectivity, from a post-structuralist perspective, meanings shared between human beings exist only within the closed system of language, and are unpredictable and characterised by difference (Callinicos, 2007). The post-structural subject, understood as subject to meaning within discourse, is also shifting and always in a process of change, rather than being the self-referential source of its own experience (Belsey, 2002; Hall, 1996). Whilst recognising critiques of post-structuralism's focus on language, to the exclusion of other aspects of experience (Howarth, 2013; Belsey, 2002), it is through this lens that the findings of the present study are examined, in relation to the findings of the review of the existing literature. Limitations in the conceptualisations of concepts of voice, culture, identity, agency and nomadism, as problematised by post-structural thinking, are considered in section 6.5, in addition to limitations discussed in sections 1.8 and 7.3.

6.2 Life in a new country

Roma people belong to some of the most marginalised groups in the world (van Baar, 2018, 2011a; Hancock, 2002; Fraser, 1995). The entire literature about every aspect of their lives, including health and well-being, speaks of prejudice and discrimination towards the Roma, and of their marginalisation. In terms of processes of 'othering', particularly in relation to western concepts of modernity and tradition, Roma people could be said to be 'hyper-othered'. Frequently deprived of the certainty of a recognised ethnicity (NICE, November 2018; van Baar, 2011a; Acton, 2004; Willems, 1997; Fraser, 1995; Okely, 1983), Roma people occupy a position beyond that of many communities struggling for recognition and equity in the face of racism, prejudicial discourses and the resulting structural inequalities.

The very existence of the present study is testament to some of the extreme difficulties faced by Roma people throughout Europe.

Yet, despite this, the findings of the present study suggested a somewhat different perspective on the part of the Roma participants themselves. For the participants, although they spoke about marginalisation and its effects (Marcin), and about their experiences of prejudice and discrimination (Pansela, Mirabella, Margaryta, Kristina, Debora, Daniella), the primary identifications they presented did not appear to be as victims of their marginalised position. Instead, the stories told by the participants were those of people who saw themselves as making a life for themselves and their families in a new country and using their own agency during the processes of adaptation to these new lives. This perspective, of Roma people as one community alongside the vast array of other communities in the UK, was largely unrepresented within the literature on Roma health and well-being in the UK. Exceptions to this were the articles by Smith (2018), Clark (2014), the Equality Commission for Northern Ireland (2014), McNulty (2014), and Tobi et al. (2010), all of which did locate Roma people in the UK alongside other cultural groups.

In addition, the voices and views of Roma people were poorly represented in the literature regarding the health and well-being of Roma people in the UK (See Appendix C.) This was also the case within the wider European literature, although the updated literature review showed an increase in the voices of Roma people, in relation to Roma representation, as well as health and well-being (Franz, 2021; Cohen, 2021; Varga, 2020; Balogh et al., 2019). One outcome of this was a limited sense of Roma agency in relation to their health and well-being. The assumed marginality of Roma people resulted in their collective representation as somewhat passive and unable to take responsibility for their own health and well-being experiences and outcomes. However, the findings conveyed a group of individuals using their own agency to take responsibility for their experiences and to develop strategies for understanding and improving these (Moreno-Leguizamon and Tovar-Restrepo, 2021; Howarth, 2013; Hall, 1996).

The Roma participants spoke of their experiences of migrating to the UK, and of their lives in London, in relation to their own, their families' and their communities' health and well-being. The health and well-being experiences that the participants described were framed within the context of migration, of negotiating the requirements of more than one culture, and of trying to do what was expected of them. The participants reported the difficulties that they faced, such as a lack of education, difficulties with communication, prejudice within the healthcare system and the wider society, and the broader complexity of modern life and its impact on the health and well-being of people from all communities: '…I think it's not just about Roma people, I think it's all about all people, it's about the food we are eating now, it's junk food, it could be modified…' (Samuel). Overall, the participants presented themselves as people actively engaging with their situation, in order to obtain education, improve their lives and those of their children, and plan for their futures in their new country. A key aspect of this process of adaptation was that of identifications made by the participants with members of other minority groups in similar situations.

Alongside this, a consideration of the problematics surrounding post-structuralist thinking about identity and processes of identification (Howarth, 2013; Hall, 1996) enables the findings to challenge received ideas about the position, abilities, and potential of Roma people, in London, the UK and more widely, in relation to their health and well-being. A post-structuralist focus on language and meaning can illuminate what is written and said about Roma people's health, as well as what the Roma participants of the present study, themselves, said about their health and well-being experiences. In turn, this interest in the use of language might be translated into changes in the ways in which Roma people are listened to, and spoken to and about, as well as their engagement in processes of policymaking and planning, in the context of health services in London and throughout the UK. A post-structuralist approach allows the discourses, narratives and myths that have created, and continue to maintain, the marginalised position that Roma people occupy to be deconstructed (Barthes, 1972).

Initially, literature published between 2000 and 2016, looking at the health and well-being of Roma people in the UK, was examined. Among the key findings of this review was the negative impact of a lack of NHS monitoring of Roma people by ethnicity on their effective inclusion in healthcare strategies and services (Fekete, 2015; European Commission, 2014a; Lane et al., 2014; Ryder and Cemlyn, 2014; Mathur et al., 2013). In addition, the findings showed a weak response by the UK to the EU requirement for a National Roma Integration Strategy (Fekete, 2015; European Commission, 2014a; European Commission, 2014b; Lane et al., 2014; Ryder and Cemlyn, 2014; Willers and Greenhall, 2012), together with a very limited and inconsistent approach to the health and well-being of Roma people across the four nations of the UK (European Commission, 2014a). The overall result of this lack of inclusion was a sense of the invisibility of Roma people within mainstream provision for health and well-being in the UK. The literature showed Roma people as being virtually absent from the NICE guidelines (July 2016, September 2015), and categorised within a somewhat marginalised position, whereby they were separated from other minority ethnic communities and, instead, included in collectivities described as socially excluded (Department of Health, 2010) or vulnerable (Davis and Lovegrove, 2016). More recent literature showed continuing uncertainty with regard to the catgorising of Roma people (Campos-Matos and Mandal, 2021; Ministry of Housing, Communities and Local Government and Lord Bourne, 2019; WEC, 2019; Ministry of Housing, Communities and Local Government, 2018).

This oscillation between a recognition of Roma ethnicity and its rejection in favour of positioning Roma people outside mainstream society can be traced from the sixteenth century to the present day (Acton, 2004). The marginalisation of Roma people carries meanings of both disadvantage and of stigma and parallels the positioning of the Roma between development and security (van Baar, 2018). In the case of the Roma, the term 'migrant' (Ruz, 2015) appears to serve as a bridge between racialising discourses regarding mobility for the purposes of immigration, and discourses relating to nomadism. One aspect at the heart of these narratives is political control of public and private space (Monbiot, 2022, 2020). The migrant status of Roma people in the UK was brought sharply into focus in 2016 with the referendum on membership of the EU (Morris, 2016). This experience was reflected in the findings by the participants, who spoke of the negative impact on their mental health and well-being of this profound change to their position in London (Margaryta, Paulo). Following the Brexit result, public space for Roma people in the UK became less safe, as anti-Roma discourses were articulated more openly by some: 'Soon you're going out from here… You're from Romania, you're Gypsy' (Mirabella).

The difficulties experienced by Roma people in London when applying for British citizenship, and described in the findings by Florin, were echoed at the RSG AGM in November 2020, in relation to the process of application for UK settled status. Recent literature echoed these difficulties (RSG, 2021a, 2020; Stalford and Humphreys, 2020; Perraudin, 2018; Zawacki, 2018). Problems resulting from Brexit were exacerbated by, and became interrelated with, those produced by the Covid-19 pandemic (Pollack, 2021; RSG, 2021a, 2021b; Walker, 2020; Matache and Bhabha, 2020; Zawacki, 2020; Korunovska and Jovanovic, 2020; Hetherington et al., 2020).

Both the generic and the health literature examined showed Roma people in the UK to be marginalised in relation to other cultural groups, despite their own recognition of their shared experiences, as recounted by participants of the present study, with Roma mobility and traditional culture both being perceived as preventing positive development in all areas of their lives, including their health and well-being.

The use of Deleuze and Guattari's post-structuralist concept of nomadism (1987) to consider the forceful threat that may lie behind a fear of nomadic life and nomadic people, can help to explain the ongoing marginalisation of the Roma. A significant aspect of this marginalisation is the prejudice and discrimination shown towards Roma people for many centuries. Both the existing literature (Zawacki and Ferranti, 2021; National Roma Network, 2017; RSG, 2012; Tobi et al., 2010) and the findings of the present study show that this discrimination has a powerful negative impact on the mental health of members of Roma communities (Marcin). In addition, the ongoing ambivalence shown towards the Roma regarding their ethnic status results in their exclusion even from the processes of inclusion of minority ethnic groups in public services, including healthcare services.

The literature regarding Roma health and well-being in the UK (RSG, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2015; Lane et al., 2014; Wright, 2011; Tobi et al., 2010), as well as the findings of the present study, showed Roma people facing many barriers to accessing healthcare services. Recent studies (Humphris, 2019; Greenfields and Dagilyte, 2018; Morell et al., 2018; Nagy, 2018) showed forms of governance of Roma people in the UK contributing more broadly, although less directly, to poor health and well-being outcomes. This thesis argues that the positioning of Roma people as marginalised, vulnerable or 'hard to reach', in relation to public services, serves to make their inclusion within mainstream healthcare in the UK more, rather than less, problematic. Butler's (2020) analysis of the term 'vulnerability' sits well with the findings of the present study, whereby participants clearly expressed their own wish to challenge positionings of Roma people as other and as separate from a range of groups with whom they identified. Their determination to use their own agency to resist such categorisations was one of the strongest findings of the present study.

The focus of the present study on the voices of its participants, and on the language used to speak about Roma people in relation to health and well-being, suggests that a greater attention to the use of language might enable the Roma to experience a greater benefit from public healthcare services in the UK than is at present the case. Much of the earlier literature, both generic and in relation to health and well-being, positioned Roma people as qualitatively different from, and therefore marginalised from, other people, with the more recent literature challenging this overall picture (Cohen, 2021; Orton et al., 2019; McFadden et al., 2018a; Smith, 2018). This sense of extreme difference was also challenged by the findings of the present study, whereby its Roma participants aligned themselves with people from other groups, including members of groups constructed as immigrants to the UK. The participants presented themselves alongside others, in terms of their experiences, their health and well-being needs, and their strategies for improving their situations. The agency of the participants, in adapting to the challenges of both migration and marginalisation, was evident.

A key finding of the present study suggested that the participants used processes of identification as a way of repositioning themselves in their new country, away from marginalisation, by establishing similarities between their own and others' experiences. This finding strongly challenges any essentialisation of Roma identity. A wide range of health and well-being experiences and concerns were reported by the participants, reflecting those existing within the wider population. It is argued here that, where differences do exist in the Roma health and well-being experience, these are primarily the result of historical and ongoing prejudice, discrimination, and marginalisation constructed by processes of othering and essentialising, as well as a failure of healthcare services to cater for the cultural needs of members of many communities, rather than anything specific to Roma people. In addition, not all Roma people living in London are excluded from healthcare services. Educated participants reported processes of exclusion, based on adherence to Roma cultural practices, for other Roma people in London, which they, themselves, were unaffected by. The education received by Nicolae and Samuel seemed to enable them to position themselves differently from others in their communities, thereby creating a differentiated, educated group within the wider Roma collectivity.

A strong thread running through the findings suggested that questions of identity and identification were highly significant to the health and well-being experiences of the participants. The participants spoke about Roma identity in relation to prejudice and discrimination (Margaryta, Pansela, Daniella, Kristina, Debora, Marcin), and in relation to migration and the impact of cultural change across generations, in particular difficulties facing young Roma people (Pansela, Artur, Margaryta), and difficulties experienced by older

Roma people (Sabrina, Paulo, Agata, Dana). Problematic issues discussed included struggling with identity, questioning identity and hiding identity. Alongside this, participants also described processes of identification with and empathy with others, including members of other minority ethnic groups, 'English people', all mothers, and *all* people. Both linguistic and cultural commonalities with others were identified by participants (Paulo, Samuel, Margaryta), and a desire to help others, both Roma and non-Roma, was also communicated (Paulo, Marcin, Florin, Samuel, Nicolae, Margaryta). The findings of the present study suggested that Roma people are, perhaps, not as 'other' or as different as many representations of them portray. Additionally, the findings present an interesting relationship, on the part of the participants, with processes of identity formation or identification (Howarth, 2013; Hall, 1996).

The participants of the present study reported developing strategies, making identifications with others, taking responsibility, and acting, rather than behaving passively, in relation to their health and well-being experiences in London. In other words, they described processes of adaptation to life in the UK, both individually and collectively. A consideration of understandings of the concept of identity within the post-structuralist tradition enables these findings to be examined. Hall (1996: 4) suggests that, from a post-structuralist perspective:

> …identities are never unified and, in late modern times, increasingly fragmented and fractured; never singular but multiply constructed across different, often intersecting and antagonistic, discourses, practices and positions. They are subject to a radical historicization, and are constantly in the process of change and transformation.

Here, identity is understood as constantly being recreated and altered, and as a site of change, growth, and political positioning:

> Though they seem to invoke an origin in a historical past with which they continue to correspond, actually identities are about questions of using the resources of history, language and culture in the process of becoming rather than being: not 'who we are' or 'where we came from', so much as what we might become, how we have been represented and how that bears on how we might represent ourselves (Hall, 1996: 4).

Whilst the past can inform an understanding of the experiences of Roma people, a post-structuralist perspective on identities stresses their historical and cultural contingency, thereby challenging essentialising constructions, and changing the focus towards the present and into the future. It is this formulation that lies at the heart of the present study. It follows that representations of the Roma can be changed, both by Roma people themselves and by others. Identities can be coexistent, contradictory and strategic, and this plasticity of identity and positioning was evident at the ACERT conference on Gypsy, Roma and Traveller identity, held in London in September 2016. The identifications with others made by the participants of the present study might be understood as both a reflection of genuine shared experiences and as a strategy towards repositioning popular perceptions of Roma identity. Such repositionings can take many forms. In a study of indigenous women's experiences in Colombia, Tovar-Restrepo and Irazábal (2014) describe the disruption of traumatic events as a space in which radically new identities can be established. The women they spoke to described putting aside issues of diversity, and utilising mechanisms of strategic essentialism (Landry and MacLean, Eds., 1996), in order to join together to successfully develop new enterprises beyond their ethno-gender-based domestic roles.

In addition to the work of Foucault (1986,1985) and of Butler (1993,1990), analysed by Hall (1996), Howarth (2013) allows the relationship between structure and agency to be considered further. Howarth seeks to develop a post-structuralist approach, in order to apply this to practical problems in the social world. In relation to the distinction between identity and identification, Howarth (ibid: 246) offers a conception of identity as referring to '…the *subject positions* – the sedimented forms of identity – with which social actors identify in their ongoing social reproduction' (original italics). He proposes (ibid: 246) that:

> …by articulating the psychoanalytic notion of identification with certain aspects of existentialism… it is possible to develop a dynamic model of structure and agency, in which agency and freedom are connected to the failure of socio-symbolic structures to determine fully the identities and practices of social actors. Subjectivity in this conception is not simply a certain "position" within a discourse, but a *radical space* in the social order that is itself constitutively incomplete and split (original italics).

Processes of change can thus be conceptualised in relation to structure, which is always unstable, and individual agency, as this relates to moments of resistance and transformation. Both Howarth (ibid.) and Hall (1996) offer approaches within the post-structuralist tradition, which enable the identifications made by the participants of the present study to be understood from a theoretical perspective. Early childhood formation of subjectivity is not the end of the process; new identifications are made throughout life and the totality is an ongoing, and always unfinished, process with, however, limitations:

> From my perspective, identities are strategic *constructs*, but constructions that are always more or less sedimented in any particular conjecture. Such degrees of sedimentation make possible the production of new identities, but do *not* allow all and every possible form of identification to be actualized (Howarth, 2013: 251, original italics).

In Howarth's (ibid: 246) approach, it is at moments when the social order, and the discourses that constitute it, fail to offer individuals a position within discourse with which they can comfortably identify that new identifications are made:

> This conception of subjectivity is predicated on the dialectical interplay between a *lacking* subject, the rendering visible of incomplete social structures by various *dislocatory experiences* that befall a subject, and a logic of *identification* in which subjects are forced to *identify* with new objects and discourses to fill the void made visible by a dislocatory event (original italics).

This, surely, is the situation in which the Roma participants of the present study found themselves, when negotiating the complexities of their lives in a country other than that in which they were born. Already occupying a marginalised position in their countries of origin, or those of their parents, life in a new country constitutes what Howarth (ibid.) describes as a 'dislocatory experience'. Fully aware of the narratives that surround their communities, both historically and in the present day, the Roma participants described their health and well-being experiences within this context, in which Roma people are subjected by discourse to negativity, to ongoing prejudice and discrimination, and to an essentialist mythologising of their culture and lifestyle. Roma people, in all circumstances, perhaps, lack an adequate range of positions within current discourse with which to identify. However, the experience of migration to a new country opens up gaps in the discursive structures, forcing the participants to seek new identifications, in an attempt to satisfactorily place themselves in their new home. In the context of health-based infrastructures in southeast England, Moreno-Leguizamon and Tovar-Restrepo (2021) make more complex the causal notion that stigma simply excludes. Instead, they suggest that '[s]tigma is seen as a catalyst of new forms of identity in which social groups contest and try to overcome stigmatisation' (ibid: 2). This conceptualisation, of stigmatised identities being negotiated and renegotiated in relation to existing structures, was reflected in the findings of the present study.

The present study argues that, aware of the marginalised and mythologised status of their culture and communities, the Roma participants sought to reposition themselves, and to represent themselves in a more positive light. They are not alone in this, as the experience of migration is always one in which existing identities are thrown into question (Belsey, 2002; Bhabha, 1996). However, Homi K Bhabha (1996: 58) points to the power differentials that lie within these inter-cultural dynamics. For the Roma, who lack narratives of post-colonialism with which to articulate experiences of 'cultural hybridity' (ibid: 58), processes of adaptation to migration are perhaps particularly challenging. Yet, the health and well-being experiences described in Chapter five, and the positivity expressed by the participants when describing them, notwithstanding the difficulties they encountered, are indicative of change and adaptation. Van Baar (2018) has critiqued the assumption that Roma people are unable to adapt, as their culture is viewed as traditional, homogenous and static, and this critique is supported by the findings of the present study. As described by Hancock (2008), Roma cultural groups are both highly heterogeneous and influenced strongly by the cultures of their host communities, across Europe and beyond. Not only is a single origin of Roma people contested (ibid.), but their global diasporic experiences guarantee cultural change and diversity. Roma history itself offers a profound challenge to the myth of a unified, discrete and unique Roma culture, and the Roma experience provides its people with resourcefulness and the ability to adapt. Indeed, the ability to adapt and to self-manage has been suggested as a definition of health (Jambroes et al., 2015; The Lancet, 2009).

The participants of the present study reported many instances in which they endeavoured to adapt to their lives in London, in order to benefit their own, their family members' or their communities' health and well-being. In addition to making identifications with others, with whom they believed they shared similar views or circumstances, they spoke also of strategies developed in order to improve their experiences, and of many instances in which they took responsibility for the situations in which they found themselves. These included learning new languages, gaining education, finding work, supporting each other, changing a job to be in a day-to-day context in which English could be learnt, sending their children to school, and choosing an English boyfriend. The adaptability of the Roma participants was evident throughout the findings. A particularly significant aspect of adaptation to western European life related to mental health conditions and their treatment. A key aspect of the literature on Roma health and well-being, both in the UK and more widely, was the negative impact on Roma mental health of centuries of prejudice and discrimination (Zawacki and Ferranti, 2021; National Roma Network, 2017; RSG, 2012; Tobi et al., 2010). The findings of the present study suggested that, not only was this the case, but also that the adaptability of the participants offered ways to overcome this collective disadvantage. Whilst the participants described mental health difficulties as presenting a problem, due to cultural prohibitions on recognising and speaking about these, they also reported processes of adaptation to the use of mental health services and therapies (Nicolae, Margaryta and Elise, Debora and Daniella).

Rose's (1999) understandings of the importance of the psychological sciences in governing human beings relate closely to Foucault's notion of bio-power (van Baar, 2011a). The necessity for individuals to manage themselves and their own psychological, as well as physical, health, in order for modern governments to maintain healthy and economically productive populations, requires individuals and groups to take responsibility for their own subjectivity, their health and their well-being. Where necessary, they need to understand and to access treatments for their own mental health (McDonnell et al., 2009). Whilst Roma people may be unfamiliar with talking therapies, the 'psy' professions (Rose, 1999) more generally and, perhaps, with the concept of self-improvement, the findings show the participants taking responsibility in relation to their health and their well-being.

The findings of the present study describe its Roma participants moving from positions of marginalisation, through processes of identification and adaptability, towards new positions within the discourses available to them within their lives in London. Van Baar (2011b: 210) discusses the work of a group of Bulgarian Romani activists, who '…contest the idea that the Roma are not able to empower themselves'. He notes that, in 2010, this group challenged the European Commission by stating: 'We demand putting an end to the discriminatory practice of treating all Roma as a socially vulnerable or disadvantaged group. The stigmatization of Roma as "vulnerable" in EU documents contributes to their forced marginalization' (Tahir et al., 2010, cited in van Baar, 2011b). However, it remains uncertain as to whether Foucauldian 'counter-conducts' of this type (van Baar, 2011b) will be sufficient to change modes of governmentalities within Europe, and to challenge the racism within anti-Gypsyism.

6.3 Culture and cultural change

The participants of the present study reported cultural issues both as factors contributing to poor health and well-being, and as barriers to accessing services and treatment. Roma cultural taboos, relating to gender, age, disability and mental health, were described by participants as creating difficulties for themselves, or for others within the Roma communities. Participants communicated a powerful sense of Roma people in London struggling to negotiate the UK healthcare services whist, simultaneously, respecting traditional Roma cultural requirements. Cultural factors were reported by participants as having a significant impact on the health and well-being of members of Roma communities. Within the UK literature, whilst there was wide reporting of the negative effects of socio-economic factors, such as poverty, poor housing and insecure employment, on the health and well-being of Roma people, and of prejudice and discrimination on their mental health, cultural factors were also identified as problematic (Marsh, 2017; RSG, 2017, 2016, 2015; The Social Marketing Gateway, 2013; FRA, 2012; RSG, 2012; Tobi et al., 2010; Poole and Adamson, 2008; Zeman et al., 2003; and Hajioff and McKee, 2000). In several studies, a key recommendation was the provision of Roma cultural awareness training for healthcare practitioners (Shallice and Greason, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016).

Despite these similarities between the literature on the health and well-being of Roma people in the UK and the findings of the present study, the overall picture presented by the literature was one of Roma culture as traditional and static, and of staff of healthcare services needing to understand Roma culture as different, and to accommodate specific Roma cultural requirements (Shallice and Greason, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016). On the other hand, whilst the need for cultural awareness on the part of healthcare practitioners was also noted by participants of the present study, the study's findings on this topic were more nuanced. Participants reported a range of experiences, and took up different positions, in relation to Roma culture, and health and well-being. A variety of positions, relating to intersectional combinations of gender, age and educational experience, were described, in which Roma women, particularly older women, appeared to face more difficulty than that faced by Roma men, in meeting their needs within the London healthcare system. Not only was this differentiation of experience significant in the present study's findings but, also, participants reported diversity amongst their responses to experiencing these differing positions.

Furthermore, on several occasions, participants pointed out that members of other cultural groups had similar needs, in relation to health and well-being, and that the requirements of their own culture were not necessarily Roma-specific. Moreno-Leguizamon et al. (2015: 9) identified similar issues to those reported by participants of the present study, impacting negatively on access to healthcare services for members of a range of Black and minority ethnic communities in Kent:

> …the main issues identified were language barriers, concerns about GPs' attention, lack of access to GPs in community health centres, lack of information due to time constraints, rude attitude of GPs' receptionists toward BME individuals, slow speed of referrals, need for more cultural competency (e.g., female GPs for female patients), and need for holistic screenings (e.g., diabetes checks).

In addition, the findings of the present study showed cultural judgements to be reciprocal, with participants viewing modern, western culture, particularly in relation to lifestyle and diet, as contributing to worsening health amongst members of all communities. Finally, although Roma women were expected to conform to the prohibitions of their culture, in relation to health and well-being, they were also identified by both female and male participants as holding important knowledge about health within their families and their communities. This aspect added an element of power to an otherwise intersectional location in which Roma women, particularly older, less-educated Roma women, were more disadvantaged than Roma men in relation to their health and well-being experiences. The stories told by the participants of the present study offered a more complex and less static picture of Roma culture, as it relates to Roma health and well-being, than that described in the literature. Within post-structuralist thinking, culture is understood as contingent, changing and adapting to new circumstances (Belsey, 2002; Hall, 1996), and a post-structuralist concept of culture allows these more nuanced experiences to be explored, and to be compared with discourses that present Roma culture as unchanging, uniquely different and uniquely problematic.

Overall, the present study's participants presented a picture of Roma culture as both calling for a respect for traditional practices, and as changing and adapting to the demands of new circumstances. Roma culture was seen to be moving between the traditional and the modern, rather than statically remaining in a traditional place or abandoning tradition altogether (Bhabha, 1996).

In Chapter seven, a learning alliance (Moreno-Leguizamon and Tovar-Restrepo, 2021; Moreno-Leguizamon et al., 2015) is suggested as a model for cultural exchange between Roma people and members of other cultural groups, as well as healthcare staff, in the context of local health service planning. Moreno-Leguizamon et al. (2015) note the effect of the UK Equality Act 2010 in incorporating ethno-racial diversity alongside a wider range of marginalising markers of identity. Using an intersectional approach, they stress the interdependence between ethnicity and race, and other marginalising categories, which should be taken into account when considering the needs of service users (ibid). The focus on culture, and the cultural identity of Roma people, identified in the literature regarding Roma health and well-being in the UK, privileges culture over other aspects of diversity, including gender, disability and age, in relation to Roma people (Shallice and Greason, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016). However, the findings of the present study suggest the need for a more complex reading of Roma culture, which recognises similarities with the experiences of members of other cultural groups, as well as the intersectional relationships between culture, gender, age, disability and the impact of education, reported by the participants of the present study, in relation to their health and well-being experiences and needs in London.

Whilst the studies that focused on Roma culture within the literature on Roma health and well-being in the UK were sympathetic to their Roma subjects, Europe-wide reports on Roma health sometimes contained a more critical tone. For example, the European Commission (2014b: 22) noted a range of countries reporting Roma 'cultural norms' in a negative light, in relation to Roma health and well-being, alongside a recognition of a lack of education and knowledge, seen, in some cases, as a cultural choice. This locating of health difficulties for Roma people within Roma culture itself fails to constructively recognise understandings about health that exist within Roma culture (Acton et al., 1997) but which may, in some cases, differ from those of mainstream healthcare providers. In profiling Roma people in Finland, the European Commission report (2014b: 69) states, '… linguistic and cultural differences, as well as lack of knowledge of their entitlements concerning welfare-related issues and available services are highlighted as factors which impede the access to health care services by Roma. For example, a stoic outlook on illness is ingrained in Roma culture and *according to their perceptions of cleanliness*, Roma tend to regard hospitals as dirty and unhygienic places' (italics added).

Yet, a notion of 'Roma culture' as unique, homogenous, static and existing across a European, and worldwide, diaspora is simplistic and problematic. The placing of culture at the centre of thinking about Roma health and well-being belies the complexity of understandings in relation to the formation of culture, its meanings and demands, its management, and the agency of those who are both subject to it and the subjects of its creation (Belsey, 2002). A post-structuralist concept of cultural experience sees this as mutable and constantly changing; this is similar to the way in which language is understood in this theoretical tradition. Some academic work within the small field of Romani Studies does recognise Romani culture in this way: 'Culture is not something fixed, inherited, unchallengeable, unchanging. On the contrary, it is constantly developing, enabling the self-expression of our self-realisation, re-inventing as well as representing and reproducing our ethnic identities. This is as true of Gypsies as of anyone else' (Acton, 1997: 5). However, the literature on Roma health and well-being tends to present a taken-for-granted, unified conception of Roma culture, in which either the culture itself is the primary determinant of health outcomes or is secondary to the effects of socio-economic factors and processes of racialisation. This binary discourse limits perceptions of Roma cultural experiences, and opportunities for Roma self-representation in relation to their own health and well-being.

Smith and Newton (2016) critique narrative accounts privileging Gypsy, Roma and Traveller culture as the only basis of healthcare choices made by members of these communities. They note that this assumption places the responsibility for health and well-being deficiencies with Gypsy, Roma and Traveller people themselves, rendering them 'hard to reach', and, thus, absolving governments and health authorities of the responsibility for making improvements in accessibility and appropriate planning. Instead, the findings from their research suggest that their Gypsy, Roma and Traveller participants made decisions adaptively and in response to underlying structural factors. Writing from a critical realist perspective, Smith and Newton (ibid: 5) state that a focus on ethnicity or culture alone, '… can hinder an understanding of the extent that health inequalities result from ethno-cultural and/or socioeconomic factors; the interplay between them or the direction of causal processes'. Yet, whilst offering a rare challenge to commonly expressed assumptions about Gypsy, Roma and Traveller culture in relation to health, Smith and Newton's analysis (ibid.) concentrates on the commonalities, rather than the diversity, between and within the cultures of these collectivities. In addition, through focusing on the influence of structural resources on cultural practices in the context of Gypsy, Roma and Traveller healthcare choices, apparently privileging structure over culture, their study remains ultimately within a binary framework.

Post-structuralist thinking problematises notions of fundamental binary oppositions, through deconstructing their implicit privileging of one aspect of a binary pair over its opposite (Derrida, 2001). Although, within the literature about Roma health, there was a tendency for NGOs and other smaller organisations to focus more on culture, and for the more academic studies to highlight structural issues and prejudice and discrimination, the findings of the present study suggested a range of possible intersecting factors and barriers operating together in relation to poor health and well-being amongst Roma people in London. In addition, Foucault's (2004) concept of governmentality introduces an understanding of sites of power and control, including the governance of the self, as multiple, changing and interacting. The notion of governmentality offers a way of conceptualising a greater complexity of factors influencing Roma health and well-being experiences and outcomes. The governance of Roma health does not only apply to programmes aimed at 'improvement';

it also encompasses all the aspects of life that interact with Roma health and well-being experiences (Humphris, 2019; Greenfields and Dagilyte, 2018; Morell et al., 2018; Nagy, 2018), including Roma people's own responses to their experiences and ways in which they manage their own health.

The findings of the present study, reflecting those of Smith and Newton (2016), indicated numerous influences on Roma people's decision-making, in relation to their health and well-being experiences. These included cultural, structural and material factors, experiences of prejudice and discrimination in different countries, and educational experience, as well as the theoretically problematic dimension of personal choice, or agency (Howarth, 2013; Hall, 1996). From the responses made by the participants, it was clear that Roma culture played a significant part in the landscape that they needed to navigate, in order to make the best possible use of healthcare services in London. However, although real barriers and difficulties were described, these were not always as clear-cut as they might seem. Participants were differently positioned in relation to cultural requirements, partly by tradition, and partly by their own agency.

The present study's findings suggested a collective experience of the shared discourse surrounding Roma cultural taboos, in relation to health and well-being, together with a range of individual positionings, reflecting differing sites of power. Among the comments made by the participants were those that described a need for adherence to Roma cultural rules and taboos. Yet, even within this strong cultural framework there was space for resistance and critique. For example, Nicolae, an educated man, saw these restrictions as existing for others in the Roma communities, rather than for himself. In relation to the negative impact of cultural taboos on Roma women's health, Margaryta was overtly critical: '…people die, because they didn't go to the doctor… It's wrong, but this is the way how we grew up'.

Differing sites and types of power, both outside and within Roma cultural experiences, produced different positionings and differing opportunities for Roma people's voices to be heard in this context. For example, those with disabilities or mental health difficulties were less likely to have an opportunity to speak about their experiences, since even the recognition of these conditions was, traditionally, silenced by cultural taboos. However, within the wider UK, mental health conditions also remain difficult topics for discussion, despite recent attempts to bring these into mainstream conversations (Henderson, Potts, and Robinson, 2019). Within the participant cohort, class, gender and age differences, and educational experiences, and the intersectional relationships between these, gave rise to a complex diversity of positioning in relation to Roma cultural demands, and in different circumstances. Nicolae and Samuel, who were professionally employed to support other Roma people, spoke often about cultural barriers affecting ‘them’, rather than ‘us’, their education and employment positioning them, in some ways, beyond their own communities. Whilst this was not consciously articulated, education and employment appeared to be experienced here as differentiating factors between Samuel and Nicolae and other members of the Roma communities. In other instances, participants exhibited shifting positions in relation to different aspects of Roma culture. Artur, for example, positioned himself apart from his Roma community, when describing Roma culture preventing him from talking about aspects of well-being that concerned him, regarding gender. Pansela, who, like her half-brother, Artur, had lived since infancy in the UK, distanced herself from Roma culture through her identification with her English boyfriend.

The use of a post-structuralist concept of culture also enables a more nuanced reading of the impact of changing discourses within Roma communities, with regard to mental health conditions, disability and autism, as well as the area of female reproduction. Although the participant cohort was not large enough for findings to be readily generalisable, there were strong indications that Roma women, particularly older women, faced more cultural barriers to meeting their health and well-being needs than did Roma men. Elise and Margaryta reported differing views regarding childbirth and support for mental health, with Elise perhaps occupying a more traditional position than her sister. Nevertheless, the findings overall suggested Roma women carrying more of the burden that these taboos created. Older Roma women, who were more likely to lack education and to experience communication difficulties, were particularly disadvantaged in terms of accessing healthcare services in London. Despite the important critique by Acton et al. (1997) and Acton (1998), of assumptions made about Roma women being disempowered by cultural taboos, the present study’s participants’ responses overall suggested that there were significant barriers to healthcare for Roma women in London, due to these cultural requirements together with a lack of education, and poor response on the part of services. There was no suggestion, among the participants’ responses, that Roma men might experience similar difficulties.

With regard to taboo subjects, the presence of a non-Roma female researcher inevitably affected the interview conversations with both men and women. In addition, as Chadderton (2011) and Passerini (2017) note, the researcher’s own cultural experiences both influence, and contribute to, the creation of the findings. For example, in relation to Elise's comments about shame generated by the breaking of cultural taboos, it was possible for the researcher to recognise the importance of the concept of shame to Elise, but impossible for her to share Elise's experience of its meaning. Barthes (2010) draws attention to the differences between cultures in which sexuality is defined by notions of shame, and those in which it is defined by notions of guilt. He notes (ibid: 123): '…the immense problem of the verbalization of the sexual, forbidden in civilizations of "shame", while that same verbalization is cherished – confessions, pornographic representations – in civilizations of "guilt" …'. Here, post-structuralist theorising about culture highlights profound differences between cultural meanings, which may be easy to write about but far from easy to genuinely comprehend, or to communicate. For Roma women seeking healthcare within a western European system, the requirement, for example, to speak about or to show their bodies to a man may be experienced as impossible. For healthcare practitioners, the sincerity of the need for cultural sensitivity in this context may be difficult to grasp. The understandings provided by a post-structuralist concept of culture offer a route towards finding common ground.

Yet, despite these significant difficulties, Roma women, particularly older women, were identified in the present study by both male and female participants as being a key source of knowledge about health. Participants valued the care they had received from their mothers and grandmothers, and older people more generally were said to hold knowledge regarding appropriate and effective traditional remedies, at least for less serious conditions. It was reported that many older Roma people believed traditional treatments to be more effective than modern medicines, and younger participants, also, reported traditional remedies to be effective. Roma people of all ages, who were living in London and the wider UK, and who wished to access state-provided medical care, were required to adapt to the prevailing western medical model regardless of their personal experiences or beliefs (McDonnell et al., 2009). The power of the majority biomedical approach, in relation to minority alternative medical systems, parallels the relationship between hegemonic Western culture and the less powerful Roma culture. Echoing the observations of Acton et al. (1997), regarding Romani hygiene and washing taboos, traditional Romani knowledge about health and healthcare is disregarded by those who seek to 'improve' Roma people in this aspect of their lives. Enabling equality of access to services that may be inhibited due to socio-economic factors, including prejudice and discrimination, is different from assuming a lack of knowledge among people whose culture is deemed to be un-modern.

Culture as constantly evolving, together with a post-structuralist interpretation of the relationship between knowledge and power, further enables assumptions about Roma people in the context of health and well-being to be problematised. A Foucauldian understanding of power links this always with processes of knowledge creation (Gutting, 2005) and with the discursive practices and institutions that provide particular discourses with hegemonic authority (Callinicos, 2007). The control over medical epistemologies and practices that these processes generate extends to all cultural and historical contexts, including those within Roma culture itself. However, the special status accorded to medicine by Foucault, in relation to the management and governance of populations (McDonnell et al., 2009), highlights the significance of European programmes of 'improvement' aimed at Roma people, in the area of healthcare (van Baar, 2018, 2011a). Just as van Baar (2018: 7) describes the construction of Roma people in Europe as '…the currently "underdeveloped" Roma [who] will gradually join in with "developed" majorities', cultural discourses about health held *within* Roma culture are overwhelmed by western knowledge constructions *about* Roma culture that deem Roma people lacking in ability to understand and manage their own health.

In relation to mental health, despite the cultural taboos described by participants, there was evidence of a slow and positive move towards Roma individuals beginning to be able to access mental health treatments, as reported by Nicolae, Margaryta and Elise, Debora and Daniella. A narrative of a culture as static casts its members as passive, disregarding the agency of individuals and groups, and processes of identification as moments of cultural transformation (Howarth, 2013; Hall, 1996). The need, desire and ability to adapt to new cultural requirements were very clearly voiced throughout the interviews with the Roma participants of the present study.

The participants also reported other examples of change, in relation to their management of their own health and well-being, and that of their families, and the health and well-being of the wider Roma communities in the UK. These included attempts by Roma people of all ages to access modern medicine, and to generally accommodate to the modern western medical model (McDonnell et al., 2009). One example is that of Roma women who had positive experiences of prenatal and postnatal care, and childbirth, in London hospitals, as described by Pansela, Mirabella, Agnieska, Daniella, Florin, and Marcin in the company of his wife. In other cases, in a move away from the traditional cultural requirement to hide disability, Samuel described Roma parents accessing, with support, help for their children who had special educational needs or disabilities. Sabrina and Paulo spoke of the helpfulness they had experienced when their son was given an EHC Plan.

In terms of the interests served by mythic narratives (Barthes, 1972), an epistemology that views Roma culture as unchanging, traditional and out-of-step with modernity, as critiqued by van Baar (2018), or one which places it centrally, in relation to Roma health and well-being, contributes to maintaining the marginalisation of Roma people. The findings of the present study show Roma cultural practices in London to be constantly moving between the traditional and the modern. Cultural awareness training for healthcare professionals working with members of Roma communities was recommended within the literature (Shallice and Greason, 2017; Smolinska-Poffley and Zawacki, 2017; RSG, 2016), and by participants of the present study. However, it is important that training and discussion present culture as mediating reciprocally between conservation and change, and that training in Roma cultural competency avoids conveying an idea of Roma culture as purely traditional and static.

Problematising the findings of the present study using a post-structuralist concept of culture allows existing discourses regarding Roma culture and health, about Roma people themselves, and about the health and well-being of Roma people in London, to be closely examined. This approach perhaps enables a more nuanced understanding of the complexities surrounding Roma culture, in relation to the ways in which healthcare services are structured, offered and presented. Health and well-being inequalities have complex causes, and cultural differences cannot be the assumed cause of poor outcomes (EPHA, 2014; Nazroo, 2003). However, the findings of the present study suggested that cultural practices do create barriers for many Roma people, when seeking access to healthcare services in London. In many respects, these difficulties are linked to Roma migration, and the demand for Roma people to accommodate to new cultural requirements in a short period of time. Western epistemological beliefs about culture itself, about Roma culture, and about health and well-being, situate Roma people in a place that both demands and refuses ‘change’ and ‘progress’ (van Baar, 2018; Robins, 1996). Nevertheless, the participants of the present study reported processes of cultural change and adaptation, involving the use of their own agency, despite the problems they faced in London, and the wider difficulties generated by prejudicial readings of Roma culture. In addition, cultural judgments were seen to be reciprocal, with participants articulating a view of ‘modern’ Western culture as contributing to increasingly poor health and well-being among members of all communities.

6.4 Voices of the Roma participants

Not only were the voices and views of Roma people themselves poorly represented in the initial literature reviewed on their health and well-being in the UK, but they were conspicuously absent from much of the literature describing the history of the Romani people, and the positioning and representation of the Roma in modern Europe. There was, however, some increased presence of Roma authors in the more recent literature examined (Franz, 2021; Cohen, 2021; Varga, 2020; Balogh et al., 2019). Romani history, including that of European Roma groups, contains uncertainty and debate (van Baar, 2011a; Hancock, 2008, 2002; Fraser, 1995). Much of this history, as well as current discourse about the Roma, has been written by non-Roma people, leading to a situation in which the Roma tend to be portrayed either as needing help or, more negatively, as presenting a problem for wider societies (van Baar, 2018, 2011a). With the exception of a small number of Romani authors (Cohen, 2021; Marsh, 2017; Matache, 2017; Hancock, 2008; Belton, 2005; Hancock, 2002), the story of the Roma people has not been told by Roma voices. Equally, the portrayal of the Roma as poor and vulnerable results in a tendency for research to seek out and expose Roma people as such.

In this context, the present researcher chose to focus closely on the voices and views of the participants of this study, as they reported their health and well-being experiences in London. Individual semi-structured interviews were selected, in order to give each Roma participant an opportunity to choose how much, or how little, they wished to say, and to share with the researcher the direction taken by the interview conversation. In Chapter five, considerable space was given to reporting the transcribed speech of the participants, within the analysis made by the present researcher. This was a deliberate choice, in order to highlight the participants' own voices to an extent not found within the existing literature on Roma health and well-being in the UK.

It is argued in the present study that a strong focus on the voices of the Roma participants, together with the use of post-structuralist concepts, has enabled more nuanced readings of the participants' voices, thus highlighting the diversity among their experiences. In addition, findings were identified that did not appear within the initial literature, with some being confirmed by more recent literature. Through complexifying the Roma voice, rather than presenting it in a mono-dimensional way, essentialising representations of Roma people and their experiences can be challenged. In the case of the present study, the voices of the Roma participants were understood to be authentic to themselves, within the post-structuralist conceptualisation of voice as fluid and subject to the influence of multiple discourses. At the same time, the idea of an 'authentic', unified Roma voice was problematised.

The participants of the present study shared in common the experience of having had both the 'nous', or personal agency, and the means to migrate, in search of a better life, and having obtained support from the organisations that facilitated the interviews. The participant cohort was diverse in terms of age, gender, educational experience and country of origin; nevertheless, it did not represent the whole of the Roma diaspora. The voices of Roma people unable or not wishing to leave their countries of origin were not accessible to this study, nor were the voices of highly educated Roma people examined in depth. The Roma people interviewed also belonged to different Roma groups which were associated with speaking different versions of Romanes, the Romani language. Alongside new findings, participant responses reflected, in many ways, the themes identified by the present researcher within the existing literature on Roma health and well-being in the UK. It is acknowledged that, whilst it was open-ended, the interview schedule was devised with the initial literature examined in mind, as well as being influenced by the researcher's previous experience in the fields of Gypsy, Roma and Traveller Education and Romani Studies. In addition, a post-structuralist perspective understands the literature as representing a range of discourses about Roma health and well-being, rather than as a definitive account. Immediately, all representations of Roma people, as well as any notion of a 'true', or unified, 'Roma voice' are put into question when viewed through a post-structuralist lens.

Despite these caveats, the findings conveyed a strong sense of a group of people who self-identified as Roma, who had something to say and who valued an opportunity to express themselves. This self- identification as Roma sat alongside a complex range of relationships with their countries of origin, together with that of their position in the UK. They appeared to make identifications both within, and beyond, those determined by national boundaries. The participants were actively engaged with the topic and wanted to speak about their health and well-being experiences, suggesting that they wished to be heard. In some cases, participants spoke at length, with the average time of the interviews being just under 40 minutes.

Only one Roma person who was approached to take part in the present study declined. This was on the grounds that many non-Roma researchers carry out similar studies but that nothing ever changes for the subjects of the research, Roma people themselves. The Romanian Roma activist and scholar, Margareta Matache (2017), in her critique of the 'colonization' of Romani Studies by non-Romani scholars, identifies a lack of Romani representation and the suppression of Romani narratives. Although Matache (ibid.) recognises the allegiance and contribution of many non-Romani scholars, it is unsurprising that there may be a perception amongst Roma people that 'Romani scholarship' – which, to a large extent, represents the non-Roma voice - does not exist primarily to serve their interests.

Within the initial literature looking at Roma health and well-being in the UK, the voices of Roma people themselves were poorly represented. Only three studies used individual interviews (Marsh, 2017; Willis, 2016; RSG, 2012) and, of these, direct quotations were either not included (Willis, 2016), or were very limited (RSG, 2012). Marsh (2017) included Slovak Roma participants alongside Welsh Romanies and other Travellers but did not differentiate between the views of each group in the findings. In addition, only one direct quotation was used, which was not attributed to a particular participant. Each of these three studies was very attuned to the discrimination experienced by Roma people, and all used inclusive methodological approaches. Nevertheless, the lack of the actual voices of the Roma participants is seen by the present researcher as a missed opportunity to foreground the participants themselves in the outcomes of the research. Fremlová (2009) carried out face-to-face interviews with Roma representatives and with practitioners working with Roma people, but only the practitioners were directly quoted. Not only do Roma representatives not necessarily speak for other Roma people but quoting practitioners only results in an unbalanced representation of Roma people's experiences.

A number of studies used focus groups as part of, or as the main aspect of, their method of data gathering (Newton and Smith, 2017; Warwick-Booth et al., 2017; Brown et al., 2016; Smith and Newton, 2016; RSG, 2012; Tobi et al., 2010). Focus groups can offer participants a valuable opportunity to share their experiences with others (Babatunde and Moreno-Leguizamon, 2012). However, this less individualised approach may be inhibiting for certain participants and offers a consensus view that may conceal diversity amongst the views of participants. In the case of the Roma, culturally taboo subjects are likely to be less freely discussed in a group than in an individual interview, thus limiting the opportunity for all Roma voices to be heard.

The findings of the present study challenge the methodological judgement of Poole and Adamson (2008: 49) that '[I]t was not possible to conduct interviews with Slovak Roma due to language barriers and the absence of trusting relationships between the researchers and would-be respondents'. Drop-in support workers from a local project were, instead, interviewed about Slovak Roma people's lives in Govanhill, Glasgow, a choice that, despite the support workers' experience, might well be critiqued by Matache (2017). Local service providers were also interviewed by Poole and Adamson (2008), and it is the view of the present researcher that the absence of voices of the subjects of their research was both avoidable and a significant methodological failing. This was particularly unfortunate, as it occurred in the one study within the literature on Roma health and well-being in the UK that was contextualised within a comprehensive discussion of discourses and narratives that contributed to difficulties experienced by members of Roma communities (ibid.).

Within the initial literature examined, a small number of studies engaged community members as facilitators, advocates and researchers (Marsh, 2017; Warwick-Booth et al., 2017; Brown et al., 2016; Willis, 2016). The present researcher also observed Roma clients at the charity to be very involved in peer group meetings held to discuss health topics, including mental health, and in the Forum Theatre activity at the Refugee Forum meeting held in January 2017, to explore issues relating to interpreting. When Roma people are asked to be involved in health-related projects in the UK, they seem to respond positively and with interest.

In addition to the effect of the transcription process on the recordings of the interview conversations, the use of interpreters also altered the speech of six of the participants of the present study (Barthes, 2010). In some of these cases, participants spoke partly through their interpreter and partly in English and, at one moment, the interpreter simply could not contain her own voice. Elena broke out of her role to express surprise at Agata's description of change in relation to the care of older Roma family members. Culture is contingent and constantly changing, but Elena's surprise was directed at an instance of cultural change, suggesting that she viewed culture, or Roma culture, as stable and unchanging. Elena's view of Roma culture suggested narratives that portray it as traditional and resistant to the modern and may have reflected her experiences of the Roma in Poland, her own country of origin.

Within the present study, communication difficulties were the most widely reported barrier to accessing health and well-being services in London and were, by some participants, reported as the key barrier. This reflected the findings of much of the existing literature on Roma health and well-being in the UK (National Roma Network, 2017; Shallice and Greason, 2017; Warwick-Booth et al., 2017; Brown et al., 2016; RSG, 2016; Willis, 2016; Performance and Research Team, Sheffield City Council, 2015; RSG, 2015; McNulty, 2014; Wright, 2011; Tobi et al., 2010; Fremlová, 2009; Fremlová and Ureche, 2009; Poole and Adamson, 2008). However, this difficulty is not only experienced by Roma people. Moreno-Leguizamon et al. (2015: 8) found that:

> …health needs identified for the Chinese community were related to difficulties experienced by health and social care services in assessing their needs because of language barriers. Language translation was identified as the main issue, since most of these individuals spoke Cantonese and would have required interpreters to access health services and providers. Similar findings were concerned with a culturally sensitive understanding of their notions of health and illness.

Issues with communication encompass more than the complex difficulties described by the present study's participants, in relation to speaking and understanding the English language. It is not only about vocabulary and grammar; it is also about the differing values placed upon different discourses about Roma people, their culture, their motivations, their entitlements, and the languages they speak or are required to speak, and it is about the perceptions of healthcare practitioners, interpreters and of Roma people themselves. Difficulties regarding English language learning presented a particular problem for the older Roma participants, along with low levels of education and an ensuing lack of confidence, and it was older Roma people who were reported to have the greatest difficulty in adapting to the biomedical model in London. Agata, who relied largely on her interpreter, made a plea for Roma people to be understood: '…basically the people from outside, they see Roma people, like they don't want to do something, like, to be healthy, to have good diet, but she say they don't know *how*. How to do it'. With the help of her interpreter, Agata was able to challenge a negative discourse, which suggests that Roma people do not want to be healthy, or to make improvements to their health and well-being. It was clear that she was aware of this discourse and objected to it strongly.

Within the literature, whilst language barriers and communication difficulties were identified by the majority of studies, only the RSG (2016) discussed cultural factors relating to interpreting. The importance of engagement with members of Roma communities themselves, in order to provide for the range of interpreting needs reported by the participants of the present study, was not described in the literature. Without this, those who do require interpreting in the Romani language, particularly older Roma people, are unlikely to be provided for, with the consequence of their possible exclusion from services.

For Roma people, wherever they live in modern Europe, their own and first language occupies a marginal space, where it represents tradition and emotion, rather than modernity and reason (Williams, 2010). For those who have migrated from Central and Eastern to Western Europe, the languages they speak are accorded status in reverse order by their new country. Not only are Roma people constructed as a transnational European minority, but their language, also, occupies a position of minority status. Williams (ibid: 199) notes, ‘What is, and is not, a language is very much a political, rather than a linguistic issue’.

It was, therefore, unsurprising that the Roma participants of the present study reported many difficulties with communication in relation to their health and well-being in London. They are members of a marginalised people, trying in some cases to communicate publicly with a language categorised in their countries of origin as belonging in the private domain: ‘My children speak Roma Gypsy language… is our house language… and Serbian is the one you learn in the school. Like English here’ (Margaryta). Within the present study, the provision of interpreting services in London was reported to be erratic and, where interpreters were made available, the language provided was that of the country of origin. Cultural discourses within their own communities also played into the participants’ ability to speak, or not, about their health and well-being.

Nevertheless, for some participants, London offered a relatively safer space to live, and to use their voice, than they had experienced in their countries of origin. For Samuel and Nicolae, a perceived lack of visibility of Roma people in London, a city with a culturally diverse population, made things easier and safer, and they felt freer to live and to speak. Visible, as the largest minority ethnic group in their countries of origin, where they are perceived by the white majorities as ‘dark skinned’ (Yuval-Davis et al., 2017: 1049), Roma people face hostility and prejudice on a daily basis. Coupled with anti-nomadic sentiments, which continue when Roma people become sedentary, this racialisation of the Roma designates the boundaries within which they live their everyday lives (ibid.). For fear of losing her job, Margaryta hid her Roma identity while working as a cleaner in London, where the voices of Roma singers on her phone could not be openly recognised. In this situation, Margaryta uses her own agency to overcome stigma. Moreno-Leguizamon and Tovar-Restrepo (2021: 11) problematise positively such scenarios, in which '…identity, power, stigma and citizenship are in most cases at stake'. In contrast, when running her market stall, she felt able to speak in the Romani language to her Romanian Roma customers, '… then I speak in the same language, people see me – I don't mind… I don't mind'. In this instance, Margaryta is describing the danger of drawing racialised prejudice towards herself if she is seen to be speaking the Romani language in public, but she risks this in order to help Roma customers from a country that is not her own, who are unable to speak in English.

The presence or absence of negative racialising discourses about Roma people lay behind other aspects of safe and unsafe space, where the Roma participants were able to speak or were silenced. With one exception, participants were interviewed either in their own home or in an office of a familiar and friendly organisation. Introductions to the researcher had been made by trusted professionals and, where requested by the participant, a representative or an interpreter known to them was present. The responses of most suggested that, in these spaces, it was relatively safe to speak. The only participant who was reserved on some topics was Kristina, although she seemed motivated to recount a story of experiencing stigma while supporting her mother during a hospital stay. In the case of Mirabella, who was interviewed in a coffee shop, the researcher was aware of other customers watching, somewhat uneasily. During her interview, Mirabella was protected by the presence of the researcher and her representative, but local people were used to seeing her outside, on the street, selling magazines. The present researcher had a distinct sense that Mirabella was being regarded as out of place and was uncertain as to whether she would have been able to sit in the coffee shop alone.

In the case of the present study, what does problematising the findings using a post-structuralist concept of voice tell us about existing discourses, about Roma people themselves, and about the health and well-being of Roma people in London? From the discussion above, it can be seen that a post-structuralist understanding of voice sees the representation of Roma people as complex, and that any notion of a single 'authentic' Roma voice is essentialising and questionable. In addition, the intersubjectivity between the participants and the researcher is understood to give rise to the specific discourses identified within the findings. Belsey (2002) and Hall (1996) describe the multiple and changing character of the decentered and divided subjective self, in relation to interacting categories of ethnicity, gender, age and class, and this calls for an awareness of the subtleties expressed within the participants' responses, and of the interpretations made of these, in an attempt to avoid stereotyped and essentialising assumptions regarding their health and well-being experiences.

Van Baar (2018: 9), noting widespread scholarly discussion about the treatment of Roma people as a threat to security, states that, '… they have been problematized in terms of alleged threats to public order, *public health, social security systems* and national security' (italics added). In this view, public health, and systems of social security that support health and well-being, are located beyond Roma communities. Roma people are positioned outside generalised notions of 'the public' and, as reported by the participants of the present study, are sometimes unable to access support systems. For example, Marcin and Nicolae described the difficulties experienced by Roma people in Romania, when attempting to access healthcare services. Participants reported differing experiences in Poland, with Kristina's family able to access doctors and hospitals, whilst Daniella and Samuel spoke of prejudice on the part of some Polish healthcare professionals, as well as exclusion from services for children with special educational needs and disabilities. At the same time, Europe-wide strategies have been developed, ostensibly to improve the lives of Roma people in all domains, including that of health (van Baar, 2018, 2011a). Roma people, caught between the contradictory demands of these opposing discourses, remain trapped in a place in which 'improvement' is always in the future (van Baar, 2018), and where their own views have little currency. The involvement of Roma people in determining what they believe their own communities, specifically, might need, in relation to their health and well-being, appears to be very limited.

These approaches render Roma individuals lacking certain opportunities to speak; yet participants' responses show that, clearly, they wish to do so, but that they face many barriers preventing them from expressing their own views. The findings of the present study show us that its Roma participants had diverse opinions and views, whilst also sharing common experiences, in relation to their health and well-being. It was clear that the participants knew how they are viewed by others and that they were aware of the discourses circulating about them. There was a wish to challenge these discourses, as shown, for example, by Agata and by Margaryta, and there was a strong desire amongst the participants to think seriously and in depth about their health and well-being experiences, the problems they and their communities face in relation to these, and possible solutions to the difficulties encountered.

For Roma people, in the context of health and well-being in London, thinking about voice from a post-structuralist perspective offers the possibility of new ways of thinking about them, and about how their needs might be met. The findings of the present study suggest that this could be done by health service planners and policymakers clearly recognising diversity within and among Roma communities in London. By consulting with, and listening to, Roma people both individually and in groups, the commonalities and differences within their health and well-being needs might be recognised, understood and planned for. The provision of consistent interpreting services that take account of the differing language needs of Roma people, including those who speak only the Romani language, would be a key element of improving services for members of Roma communities. The language that people wish to speak in should not be assumed. In light of the fact that people from non-Roma communities also experience communication difficulties, in relation to accessing healthcare provision (Moreno-Leguizamon et al, 2015), improvements in interpreting services across all UK health services might be a cost-saving investment in the longer term.

Careful consideration of the use of language, in relation to Roma people in the health and well-being context, could take account of the ways in which they are spoken to and about, the preparation of health-related resources for Roma people, and the representation of the Roma within training for healthcare professionals. Offering thoughtfully devised opportunities for Roma people to become better informed about health and well-being services in London would support them in becoming independent service users. Health-related education for Roma people might be offered alongside that for members of non-Roma groups, so that Roma people need not always experience ‘othering’, in relation to their ethnicity and culture. In this context, respect for traditional knowledge about healthcare, held within Roma communities over generations, would enable Roma people to participate in this process on a more equal footing. Cultural awareness training for healthcare professionals working with Roma people in London can be beneficial if it avoids presenting Roma culture as static and unable to change. Roma people living in London can be understood as adapting to cultural change and the demands of migration. Similarly, the adaptive nature of culture, including Roma culture, sees it moving in both directions between the traditional and the modern, and incorporating this understanding of Roma culture into training for healthcare professionals can free Roma people from earlier marginalising positions.

Thinking about voice through a post-structuralist lens allows us to think differently about what the health and well-being needs of Roma people in London actually are. For example, the participants of the present study reported a wide range of health and well-being experiences that, for the most part, mirrored those of members of the wider population. Differences could be understood to occur, in relation to the effects of prejudice and discrimination, rather than as a result of any significant ‘otherness’ among Roma people. A post-structuralist concept of voice enables us to listen carefully to Roma people, allowing us to challenge essentialising constructions of who the Roma are, how they think and what they do or do not need, such as, for example, a conceptualisation of people of dubious ethnic status who are certain to be ‘hard to reach’. It allows us to dig deeper into the differences and diversity amongst the views expressed by the participants, for example, in their positioning in relation to Roma cultural prohibitions, as well as those views and experiences that contradict other existing narratives about Roma people, in the health and well-being context. In addition to a post-structuralist concept of voice enabling a single essentialised narrative of the Roma to be problematised, its purpose is also to contribute to challenging the invisibility and marginalisation of Roma people’s views and understandings about their health and well-being. Van Baar (2011b: 210) suggests that: ‘…making these Romani voices audible and their struggles visible in the current debates are the first steps necessary to challenge the multiple forms of exclusion with which substantial parts of Europe’s Romani minorities are currently confronted’.

6.5 Theoretical limitations

The concepts of voice, culture, identity, agency and nomadism, problematised by post-structuralist thinking, offer a rich and unusual lens through which to examine the health and well-being experiences of Roma people living in London, in relation to narratives and discourses affecting these experiences. Nevertheless, limitations in the conceptualisations of these concepts should be acknowledged, particularly with regard to data analysis and the possibilities for positive, practical outcomes based on the findings of the present study. The examination of existing literature, together with the theoretical sections in which the concepts are described from the perspective of post-structuralist thinking, shows clear links between current narratives and discourses regarding Roma people generally, and in relation to their health and well-being. These discourses suggest that enhanced recognition of Roma people and their experiences, greater opportunity for self-representation, and the development of recommendations regarding resource distribution for the health and well-being provision of Roma migrants in London would constitute appropriate and much-needed outcomes from the present study.

However, this study sets out to answer the research question: **To what extent may health and well-being experiences of Roma migrants in London be perceived and understood through a post-structuralist lens?**, suggesting limitations to its particular theoretical approach. The broader limitations of post-structuralist thinking have been widely discussed (Howarth, 2013; McDonnell et al., 2009; Callinicos, 2007; Gutting, 2005; Belsey, 2002; Hall, 1996). Alongside this, Howarth (2013), McDonnell et al. (2009) and Hall (1996) show how a post-structuralist approach can move beyond a purely deconstructive position to support practical action. The linking of a recognition of the linguistically constructed nature of meaning with the possibility of political action by critical race theorists has also been noted (Crenshaw, 1991, 1989). The present study seeks to be, primarily, an in-depth qualitative academic study, rather than a vehicle for activism, but the need for change is built into both the study's existence and its findings.

The concepts of voice, culture, identity, agency and nomadism were conceptualised using theoretical ideas from the post-structuralist tradition. The present study did not allow space for wider post-structuralist theoretical consideration of the concepts, and it is acknowledged that these could have been further developed. In addition, conceptualisations of these concepts using other theoretical frameworks would have offered both alternative formulations and alternative readings of the findings. A wide literature exists in relations to these concepts, in particular, culture, agency and identity, and it has been possible to refer to only a small aspect of this literature.

The concepts are used throughout the discussion to amplify understandings of the findings in what is, itself, a discursive fashion, rather than being applied to analysis of the data in a more structured or forensic manner. This use offers a broad sweep through the findings from the thematic analysis of the data which, it is hoped, might contribute to greater recognition of Roma migrants in London, a broadening of space for their self-representation, and improved resource distribution regarding their health and well-being.

6.6 Summary

It has been important to note the need for reflexivity within the post-structuralist analysis of the present study. Just as Passerini (2017) describes the selectivity of interview participants in relation to their responses to what they are asked, the present researcher was also selective in her choice of topics for discussion and the interpretations made of the findings. The researcher used knowledge to create knowledge. Knowledge from the participants, as well as from a range of texts, together with the researcher's previous experiences and understandings, contributed to the knowledge generated by the study. This reading of the findings of the present study, the discussion and the conclusions drawn, is one discourse among many possibilities: 'Culture consists of the meanings its subjects produce and reproduce. Even in the process of analysing it, we are simply taking up another position in culture, inhabiting a space culture itself provides, or can be induced to provide' (Belsey, 2002: 26). Belsey (ibid.) reminds us of Barthes' (1968) essay, on the 'Death of the Author'. Readers of the present study will make their own interpretations of the meanings carried within its theoretical position, methods, findings, and conclusions. Nevertheless, it is this possibility of difference that enables a consideration of the uses of language in discourse to offer alternative representations of, and communications with, Roma people in the context of their health and well-being in London and the wider UK, and the hope for improvements in their experiences.

The concepts of voice, culture, identity, agency and nomadism, as problematised by post-structuralism, enabled the findings of the present study to be analysed in relation to the existing literature, in ways that questioned and challenged essentialising representations of Roma people. In focusing on the voices and views of the Roma participants from a post-structuralist perspective, the impossibility of locating a single, 'true' representation of Roma people's experiences became visible. The ways in which an individual voice, already the product of a subject created within discursive practices and divided from itself, is then altered through the process of research, show the unreliability of any notion of 'true speech'. Nevertheless, and bearing in mind the influence of the researcher on the interpretation of the data, there are commonalities within the findings but there is, also, a diversity of views and experiences. Any preconception of unified or essentialised thinking, on the part of Roma people, is challenged. The participants positioned themselves neither as passive victims of prejudice within the UK healthcare system, nor as hostile towards healthcare practitioners or, indeed, any aspect of their new country. They presented themselves as trying to adapt, and to find their way through the complex social and cultural landscape of their lives in London.

The analysis and discussion of the findings suggested that the Roma participants wanted to portray themselves as similar to other people. Processes of identification with others enabled them to distance themselves from the customary position of Roma marginalisation, of which they were well aware. In many respects, the participants did not position themselves as separate, or different, in the ways in which many texts about them, both written and visual, do. In relation to health and well-being, they spoke of themselves as wishing to look after themselves and their families and, generally, of seeking to do what was asked of them in their new country. Sometimes they did not know what this entailed, or they simply did not have the means or resources to achieve it. Yet, on other occasions, they utilised a range of strategies to achieve their goals, as well as critiquing the impact of modern, western culture on health and well-being outcomes. The different participants positioned themselves differently in different contexts.

It is the contention of the present study that the long-standing locating by health authorities of the Roma as marginalised or ‘hard to reach’ contributes to barriers experienced by Roma people, in relation to their health and well-being in the UK. An attentiveness to the language used by the Roma participants of the present study enabled their own health and well-being experiences to be considered, alongside an analysis of discourses currently used as these relate to the provision of healthcare services for Roma people in London and across the UK. Perhaps, through a focus on language, listening to Roma people themselves, and working with Roma people to consider the language used in health promotional materials, and to inform policy and practice, health and well-being services might be made more accessible to, and usable by, Roma people living in London and other parts of the UK. Knowledge that Roma people already hold about their own health and well-being might be utilised, through engaging with them, to facilitate improvements for all members of Roma communities, and to inform strategy and planning for the longer term. The findings of the present study suggested that Roma people in London experienced a similar, and extensive, range of health and well-being issues as would any other group. Their experiences differed from others only in relation to the effects of longstanding prejudice and discrimination and resulting inequalities. Cultural barriers presented genuine difficulties but, again, were seen to be similar to those facing members of other communities.

A close consideration of the uses of language could support healthcare practitioners and service providers in seeing their Roma patients as requiring a similar approach to that offered to other groups of patients. Roma people living in London have been shown in the present study to be adaptive to change, and to the demands of migration. The participants portrayed themselves as similar to members of non-Roma groups and may not always be in need of the ‘othering’ that specific, culturally targeted approaches necessitate. Alongside a more positive inclusion of Roma people, it is important to hold in mind the idea that a one-size-fits-all approach to healthcare provision may not be the most appropriate model in a country with a diverse and cosmopolitan population. Wide ranging consultation with *all* service users, and caution in relation to language use, might lead to improvements in service design and provision for all. It may not be only service users that need to change, but services themselves. The present study focuses on Roma people living in London, and its outcomes relate to the health and well-being needs of Roma people in London and, perhaps, the wider UK. The probability is that members of Roma communities in other parts of Europe have different experiences to be listened to. However, the learning alliance model (Moreno-Leguizamon and Tovar-Restrepo, 2021; Moreno-Leguizamon et al., 2015), together with a significant focus on language use, offer possible ways forward for Roma health and well-being in the UK.

CONCLUSIONS

7.1 Introduction

The present qualitative study looked in depth at the health and well-being experiences of Roma adults living in three London boroughs. It sought insights into the relationship between the findings of the literature review, including the contextualising literature, and those of the fieldwork, through problematising these using the concepts of voice, culture, identity, nomadism and agency from a post-structuralist perspective. Chapter seven now offers some conclusions, drawn from the outcomes of this process, together with a consideration of the strengths, limitations and original contribution of the present study. Suggestions for the practical application of the findings and conclusions within the UK healthcare context are also proposed.

7.2 Conclusions drawn

- The impact of Roma historical and cultural experiences on the health and well-being of Roma people in London is significant. However, an overemphasis on narratives that separate Roma experiences from those of other communities may detract from a recognition of similarities between health and well-being experiences of Roma people and members of other groups. The present study's focus on the voices of its Roma participants enables their use of processes of identification with non-Roma people as a way of repositioning themselves in the face of prejudicial and marginalising narratives to be recognised and acted upon.
- The approach used within the present study enables a shifting of focus from the traditional interest in Roma history, identified within the literature, into the present and towards the future, for Roma people in London, in relation to their health and well-being. This supports a change in narrative, beyond an idea of 'traditional' Roma culture as static and unchanging, to one of Roma culture as constantly shifting between the traditional and the modern and adapting to new circumstances.
- The consideration of the findings of the present study, using concepts problematised from a post-structuralist perspective, calls for an alertness to the relationship between narrative and discourse about Roma people, and Roma health and well-being, and their own reported experiences.

- This focus on language suggests that consideration of the ways in which language is used, in the context of Roma health and well-being in London and the wider UK, might lead to improved services, experiences and outcomes.
- The findings of the present study suggest that the reification of the categorising of Roma people as vulnerable or 'hard to reach' contributes to their ongoing marginalisation.
- Recognising Roma people within the context of migration and adaptation to new experiences, rather than as a supposed unique case, may support them in positively repositioning themselves, in relation to their health and well-being, and in other areas of their lives.

7.3 Study strengths, limitations and original contribution

Strengths and limitations of the study design

- The scope and limitations of the present study were outlined in Chapter one and are developed here.
- The present study concentrates on the health and well-being experiences of Roma people living in three north east London boroughs. It does not report on the experiences of Roma people in other areas of London, or of the UK. The limitations of this northeast London location do echo limitations identified within the existing literature. Opportunistic sampling was undertaken with self-identified Roma adults, who had lived in London for a number of years, and the interviews were accessed through their relationships with staff of organisations supporting Roma people, within the public and the voluntary sectors. Whilst this group was diverse, in terms of gender, age and country of origin, this approach provides data on the experiences of a particular group, within a focused geographic area of London.
- The findings of the present study are not necessarily generalisable to Roma throughout the UK, who may have different experiences, although aspects of the existing literature are supported by the findings, suggesting some degree of shared experience. The findings are also not representative of very recently arrived Roma people in London, nor of the Roma in other European countries. Neither does the present study report on the health and well-being experiences of English or Welsh Romanies, or Travellers of Irish or Scottish heritage. It was not the intention of the

present study to undertake research into the experiences of members of these other groups.

- Insights gained through voluntary work add to the trustworthiness and credibility of the analysis and interpretation of the findings of the present study.
- The need for reflexivity is an integral aspect of a post-structuralist theoretical approach. The influence of the present researcher on the study design and interpretation of the findings is acknowledged. This particular study offers one theoretical focus out of a range of possibilities, and tells one story, again out of many possibilities. (See Appendix A for reflexive observations.)
- The present study uses a qualitative methodology, rather than quantitative or mixed methods. This is not a large-scale survey, but one that allows for an in-depth study of the experiences of a particular group of participants. Semi-structured interviews, with open-ended topics, offered space for the voices and views of the 19 Roma participants to be studied in detail. The implications of changes made to the study design were considered in section 4.6.4.
- The need for translation and interpreting, in order to carry out the present study, could be viewed as a limitation. Whilst it was understood that this situation might restrict the participants' ability to express themselves, interpreters were known to the participants and translations of the consent form and information for participants were made by members of the participant group. In addition, the complexities of working with a wide range of languages was seen as a strength of the study, as it offered varied perspectives on the topics discussed.

Strengths and limitations of the theoretical framework

- The theoretical framework for the present study was based on post-structuralist thinking. Post-structuralism has been critiqued for its location of meaning within language, carried by discourse, thereby excluding other aspects of experience highlighted by other theoretical approaches. For example, critical realism, or a Marxist approach, would be directly interested in structural influences on experience. However, the concepts of voice, culture, identity, agency and nomadism, from a post-structuralist perspective, were specifically chosen, as each relates directly to key aspects of representations through discourse of the Roma, by non-Roma people and by Roma people themselves. This choice enabled the findings from the literature review and from the fieldwork to be problematised through a theoretical lens that had not been used within the existing literature on the health and well-being of Roma people in the UK.

- The impact of material factors, such as poverty, poor housing and poor nutrition, on the health and well-being of Roma people across Europe is in no way denied. However, a post-structuralist approach suggests that narrative and discourse play a significant part in determining the politics that lead to differential distribution of material assets. In the case of the Roma, prejudice and discrimination, in particular, lead to impoverishment and precarity in the lives of many people and communities. This view is supported by the emphasis placed by the European Commission (2017) and the Open Society European Policy Institute (2017) on combating anti-Gypsyism and racism, as a precondition for the successful inclusion of Roma people in all areas of their lives.
- Whilst the present study's theoretical frame inevitably leaves out other possible theoretical positionings, some of these already appear within the existing literature on Roma health and well-being in the UK. In addition, a focus on discourse, narrative and language use offers an alternative reading of the existing literature, much of which focuses heavily on the influence of structure or of culture on Roma health and well-being, rather than on a broader range of interacting factors.
- A post-structuralist interest in language allowed the present study to concentrate on narrative and discourse, as these relate to Roma people, and on the voices of the participants of the present study. Since Roma people are represented in the popular imagination by a vast array of narratives, many of which paint a negative picture of their communities, an examination of language use in relation to Roma people was relevant to the present study of Roma health and well-being experiences in London.
- Post-structuralist thinking has also been critiqued for failing to provide sufficient practical application of its ideas, as it is seen as deconstructing existing narratives without offering alternative solutions (Howarth, 2013; Jones-Devitt and Smith, 2007). The present thesis, however, argues that a focus on language is completely relevant and important, in relation to Roma people in the health and well-being context in London and the wider UK, and offers immediate practical opportunities. In addition, the work of Howarth (2013) develops post-structuralist thought towards greater practical application.

- Furthermore, the post-structuralist tradition has been strongly critiqued for positioning subjects in a place where discourse acts upon them, and their opportunities to act using their own agency are limited (Howarth, 2013; Callinicos, 2007; Gutting, 2005; Hall, 1996). However, Howarth (2013) and Hall (1996) develop post-structuralist thinking about the relationship between the subject and discourse, in ways that suggest scope for agency on the part of individuals and groups, and these ideas have been explored within the present study.

Original contribution

- The present study makes an original contribution to thinking about Roma health and well-being experiences in London. To the present researcher's knowledge, no other study of Roma health and well-being in the UK uses a set of concepts from a post-structuralist perspective to problematise its findings, in relation to the existing literature.
- The present study offers a focus on language use and voice in the context of Roma health and well-being in London, which moves away from the broader focus on cultural and structural factors within the wider literature. The theoretical framework of the present study allows for a focus on discourse and narrative about Roma people, an analysis of the voices of its Roma participants, and a practical consideration of the use of language, in relation to Roma people in the UK healthcare context.
- The findings of the present study offer an alternative to the focus within the existing literature on Roma cultural barriers to healthcare, and on structural factors impacting on Roma health and well-being. The significance of both of these aspects of experience is recognised. However, the present study sees language use, discourse and narrative as playing a central role in shaping tangible experiences of Roma people in London, and a theoretical focus on language as offering ways of reconceptualising its uses, in relation to Roma people's health and well-being in London and the wider UK.
- The present study, through its use of concepts of voice, culture, identity, agency and nomadism, as problematised by post-structuralism, suggests ways in which discourses about Roma people's health and well-being might move from a focus on the historical past and its 'romanticisation', and ideas about a static, traditional Roma culture, into the present and towards a future in which the agency of Roma people becomes increasingly visible.

7.4 Practical applications in the healthcare context

- The ideas arising from the discussion of the findings of the present study suggest some principles that might be used within the London and UK health and well-being context, in order to promote positive experiences for Roma people in relation to health and well-being services.
- A recognition of the significance of language use in the context of healthcare services provided for Roma people may contribute to improved health and well-being experiences for members of Roma communities. Popular discourse and narrative about Roma people, for example, may be prejudicial or romanticising, or may assume Roma health disadvantages, often in relation to an idea of Roma culture as contributing to poor outcomes. An awareness of what is written about the Roma, how they are listened to, the ways in which they are spoken to and about, and the use of language in the production of materials relating to Roma health and well-being can all contribute to improvements in Roma health and well-being experiences and outcomes.
- The health and well-being experiences of Roma people can be located in relation to migration and processes of adaptation to life in a new country. These experiences have many similarities with those of members of other groups, and Roma people are aware of their shared experiences with others. Constructing Roma people as vulnerable or 'hard to reach' can contribute to their continuing marginalisation. However, this should be balanced with a recognition of ongoing oppression, exclusion and a culture of silence regarding the health and well-being needs of Roma people.
- Involving Roma people in the planning of local health and well-being policy and services provides opportunities for their voices and views to be heard and acted upon. A learning alliance offers a model through which service users, including Roma people, might be consulted, along with people from other groups (Moreno-Leguizamon and Tovar-Restrepo, 2021; Moreno-Leguizamon et al., 2015). Whist a learning alliance might be used to consult with members of a range of Black, Asian and minority ethnic groups, including those from Roma communities, and may offer opportunities for cultural exchange, an exclusive focus on minority groups again carries the danger of marginalisation through 'difference'. Consultations may,

therefore, need to be broadened, to ensure that members of all communities are involved in planning healthcare services that recognise diversity amongst all people, and not only those from marginalised and ‘othered’ communities.

Mono-cultural healthcare services, with a one-size-fits-all model, may not be appropriate in all cases and this applies to all people.

- Roma people, in particular women of all ages, carry with them understandings about the management of health that have been developed within Roma communities over centuries. An engagement with this knowledge during processes of consultation may be helpful in avoiding imposing a medical model that could prompt the self-exclusion of some Roma people. Again, this principle might be usefully extended to service provision for a wider range of communities.
- In the context of migration, older Roma people may find adaptation to new expectations and experiences particularly difficult. They may need support with communication, with information, and with ensuring registration with a GP.

  Communication difficulties can present significant barriers for members of Roma communities, in relation to accessing health and well-being services in London. Interpreting and translation services need to be provided appropriately and in consultation with Roma people, to establish the type and level of support needed, as well as the language to be used. Again, consultation with Roma people with regard to interpreting and translation can contribute to positive health and well-being experiences and outcomes.
- A recognition of Roma cultural requirements, in relation to women’s health, mental health conditions and disability is necessary. However, this is not just a Roma issue, as Roma people share these needs with people from many other groups, including, but not exclusively, Black, Asian and minority ethnic communities. Cultural awareness training for healthcare practitioners can be helpful but should not reinforce a narrative of Roma people as uniquely different from everyone else.
- Following on from this, it is important to recognise that culture is constantly changing and adapting to new circumstances. This includes Roma culture. In this view, Roma people can be seen as inhabiting the modern world, rather than as being caught within an idea of a static, traditional past. Within Roma culture lies knowledge about health and well-being, which can be utilised in the present time. Understandings about health, held by Roma women of all ages, could be included in

planning for healthcare provision. Where Roma beliefs about health differ from those of the mainstream biomedical model, an openness towards their ideas and experiences may be fruitful in building positive relationships between Roma people and healthcare practitioners.

- A more nuanced awareness of the health and well-being experiences and needs of Roma people is achieved through intersectional understandings, in which positive, as well as negative, factors may intersect. For example, whilst older Roma women may be subject to cultural prohibitions regarding Roma women's health, and exclusion due to a lack of education and communication difficulties, within their communities, older Roma people carry respect and Roma women are seen as knowledgeable about health matters. Younger Roma people, born or brought up in the UK, may have complex relationships with traditional Roma culture but may also be more able to negotiate life in the UK than their parents and grandparents.
- As an overall principle, enabling equality of access to services that may be inhibited due to socio-economic factors, including prejudice and discrimination, can be seen as different from assuming a lack of knowledge among people whose culture is deemed to be un-modern.

7.5 Summary

Romani people may have a unique history, although even this is open to debate, but constructing them as a unique people, by supporters and detractors alike, serves to keep them in a place of difference from others. The findings of the present study suggest that migrant Roma people in London - those who found and have taken the opportunity to seek a better life for themselves and their family - wish to adapt to life in their new country, and to take responsibility for their own health and well-being. However, a key factor standing in the way of their success, are the ways in which Roma people are spoken and written about, and the meanings made from the narratives that surround them. The stories told by the participants in the present study offer alternative ways of speaking to and about Roma people. Reframing the narratives we use, and focusing our language on constructive outcomes, can help Roma people in London and the wider UK to reposition themselves, in order to have the same opportunities as others in relation to health and well-being experiences and healthcare services. As a diverse cultural collectivity, in a plural, diverse society, Roma people will still face broader difficulties relating to equality and political power. However, if health service literature speaks of Roma people as proactive, cooperative and responsible members of London and UK society, rather than as a difficult-to-manage anomaly, the very real agency that they display should enable them to help themselves towards much improved health and well-being outcomes. The inclusion of Roma people in processes of planning for UK health and well-being services and provision could allow the richness of their voices and views to be heard, and to contribute to improved experiences for all users of these services. The present study offers an original contribution to thinking in this area, which suggests that ideologies and discourses can change, structures can change, and Roma health and well-being experiences in London and the wider UK can be improved through a serious focus on the uses of language in relation to Roma people in this context.

General reflections on the MPhil/PhD process

I have chosen to write this section in the first person, for reasons that will be apparent. Its focus is some personal reflections on the relationship between practice and theory, the experiences of research participants, researcher and intermediaries, and the position of the researcher.

Practice and theory

For a long time, I have strongly believed that practice and theory should inform, and be informed by, one another, and that one without the other lacks an essential dimension. Following an early career as a primary school teacher I moved, almost by chance, into the field of Traveller Education, where I coordinated educational support services for Gypsy, Roma and Traveller children across two London boroughs. I did this work for seventeen years.

The posts I held were richly rewarding in many ways, particularly in terms of the relationships I made with not only the children but, also, the adult women. I met fathers and grandfathers as well but, within the Gypsy, Roma and Traveller communities, it is the women who deal with matters concerning the children in school. I came to know people I would never otherwise have met, to visit them in their homes, often on Traveller sites, and to learn about their lives and cultures through first-hand experience. Over the course of many years, trusting relationships were built and some of the mothers and grandmothers became my friends. I knew, if I ever needed help, these people would give it with more generosity than many others I knew, and I grew very fond of them and of their children.

The experiences of members of these communities within formal education systems are complex, and are the topic of other texts, but suffice to say the work was challenging and the successes, which did come, usually took immense time and effort on the parts of all those involved. Essentially, my role was that of mediator between families and the staff of the schools the children attended, and I had to try to understand everyone's point of view. To do this, I needed to understand not only the cultures of schools but, also, the cultures of the different communities with which I worked. The ultimate aim for me and my small team was to make ourselves redundant - to facilitate the independent use of the school system by the communities and the independent inclusion of the communities by the schools. Early on, I was interested and enthusiastic, but I knew I lacked any real knowledge about these communities that might underpin and inform my practical work.

As it turned out, I was extremely fortunate to live close to a university where a respected and knowledgeable lecturer taught a module on Romani Studies, as part of a master's degree course in Gender and Ethnic Studies. I decided to apply for a place on this module as a way of gaining the theoretical knowledge I felt would underpin the work I was doing. I was accepted and so began a new aspect to my life. I found the material relevant and helpful as well as fascinating and it enabled me to bring a new depth to my work.

Not only this, but I found myself enjoying the process of studying again and, although I had intended to do just the one module and then stop, I ended up staying and completing the whole degree. In doing so, I gained a broader understanding of the concepts of gender, race and ethnicity, and of processes of racialisation. This meant I could locate my newly gained knowledge of Gypsy, Roma and Traveller communities' cultures and histories within a wider political and historical context. I began to be able to organise my thinking, so I could work within a conceptual framework that made sense to me and meant that I could give clear and logical reasons for my position and actions, when difficult decisions had to be made.

My MA dissertation was written on the subject of English Gypsy women's identities, looking at current ideas with regard to the posited Indian origin of the Romani people, the idea of a Romani diaspora and the notion of 'Romanestan', a homeland that could be established for the Romani people (Kenrick, 2007; Barany, 2001; Acton, 1994). I was working with members of Roma communities from CEE countries, as well as with English Gypsies – Romanichals - all of whom were assumed to belong to the diaspora, and I was interested in how they might view one another, and themselves, as a result of this. I carried out extended unstructured interviews with three women of Romanichal heritage, all of whom I already knew through my work.

A small number of women were invited to take part, some of whom declined. Members of the Gypsy, Roma and Traveller communities are well aware of their special status as potential subjects of researchers, writers and photographers, and some have their own policy of avoiding all such interactions. Others simply dislike the idea of being interviewed or have had a previous bad experience. It is ironic that communities so despised and maligned could be in such demand!

Clearly, the fact that the women involved already knew me meant that the dynamics were different from those where a researcher approaches participants who are strangers. Gender issues were also at play, as those who took part in my research were clearly happy to be interviewed by a woman they knew and trusted but had a man, particularly one who was a stranger to them, approached them for a similar purpose, their response might have been different. There are strong gender divisions within Gypsy, Roma and Traveller communities, with long cultural histories and, although these may be beginning to change now, under the influence of outsider cultures, they provide a code for living and can act as a defence against intrusion from those of other groups.

Interestingly, all of the women who took part in the interviews asked to be named in my study. Clearly, they had nothing to say that they felt they should hide and, rather poignantly, they seemed to think that my dissertation might be read by more than my supervisor, my examiner and my close family. Here, it seems important not to raise participants' expectations with regard to the likely impact of the research, however much it is hoped that it might change the circumstances of the participating group for the better.

In addition to the interviews, my dissertation also consisted of an account of a feud between two other women and a number of chapters, each examining an aspect of life through the lens of changes impacting on English Gypsy identity. I used a range of concepts from current sociological thinking about identity to examine and analyse the data and ideas I was working with. If I were writing the dissertation now, I would structure it more rigorously but, despite its flaws, it has a quality I value. Everything I wrote at that time came directly from my experiences with the families, their children and the staff of the schools with which I was involved. Practice was very much informing my theoretical work.

The experiences of research participants, researcher and intermediaries

When undertaking research fieldwork, ethical issues are obviously paramount. Yet the implications of these go far beyond the formal approval of university ethics boards, as well as having a direct bearing on the outcomes of the research. Participant consent forms are, rightly, standard but, even with the information given routinely to participants about the study in question, it is impossible for participants to really know in advance what it is they are consenting to.

What will the researcher actually ask them? What will the researcher's responses be? How will they feel, talking about their lives to someone they may never have met before? If they don't feel comfortable answering a particular question, will they be able to say so? And, what if they feel unhappy afterwards about having taken part and want to withdraw their information, or change some of what they have said? To have the right to withdraw is one thing but to actually return and ask for this would require a degree of assertiveness that some might find difficult. And it is rare for participants to be offered an opportunity to alter their responses, if only because of time constraints.

In addition, the researcher her or himself may feel nervous, particularly at the beginning of the fieldwork. They may need to contact organisations they are not familiar with, to ask for people's interest and time. Although some kind of incentive may be offered to the participants, such as small payments or vouchers, and the researcher may do some voluntary work for the organisation concerned, essentially the researcher is asking for a large number of favours. In particular, for a PhD, where the size of the participant cohort should be fairly substantial, this is a significant number of favours to request.

Having gained permission to carry out interviews or to be otherwise involved with their chosen study group, the researcher has to ask their questions. In the case of formal interviews, this can also be daunting, especially where there may be interpreters or representatives of the participants listening to what is being asked. Questions may, initially, be too long, difficult for participants to understand, too intrusive or repetitive and it is often only by carrying out the early interviews that these issues will be discovered. This can be an uncomfortable process for participants and researcher alike.

A further aspect to this process, which is rarely acknowledged, is the experience of intermediaries in the fieldwork. Unless, as was the case with my MA dissertation, the participants are already known to the researcher and are small in number, intermediaries are key to the fieldwork actually taking place. Nevertheless, their experiences and feelings about this are generally ignored. However, many intermediaries are practitioners who work daily with the participating group and who may have spent many years doing so. As a result, they may have a great deal of knowledge and understanding about the people with whom they work.

There are several factors involved here. Often, research participants belong to groups perceived as 'vulnerable' or 'hard to reach', and the intermediary may wish to protect them from, as they see it, being used for the benefit of the researcher. However well-intentioned the researcher may be, it can often be difficult to believe that the research will actually improve the lives or situations of those being studied. In effect, the choice of participant group as 'vulnerable' in the wider social context also makes them vulnerable to exploitation by researchers, and intermediaries will be aware of this. The whole range of power relationships is at play here, including class, race, gender and age, as well as the complex intersectionality between and among these.

In some cases, intermediaries simply refuse to engage with researchers, making it their own, or their organisation's, policy not to do so, in the belief that this will 'protect' their clients. Whether the clients involved are participant in this decision is a matter for speculation. Logically, they should be, but this may not always be the case. There is also the issue of the time intermediaries need to give to the research process if they do agree to help facilitate this.

In a busy working life, playing host to the researcher, explaining the research to potential participants, organising interviews and finding space for these to be carried out is a time-consuming process. And, if the study group concerned is of wider current interest, or exoticised as well as demonised, in the way that Gypsies, Roma and Travellers are, the number of researchers knocking on the door is likely to be large.

Nevertheless, many practitioners do welcome researchers and go out of their way to accommodate their needs. They may feel that the proposed research does have the potential to achieve positive outcomes for the study group and they may find the study interesting themselves. Over the years, practitioners may come to know academics working in the same field and may have the opportunity to develop their own understandings through this association. This is certainly what happened in my own case.

Nonetheless, the relationship between practitioner and academic can be problematic. The very terms themselves are descriptive of a hierarchical relationship. 'Practitioner' suggests practice and practical, in other words, the doing of something by physical, as well as mental, labour - getting your hands dirty. 'Academic', on the other hand, speaks of the academy, an institution of learning where those who can afford to do so study and write about their chosen area of interest. There are people who struggle financially in order to study but, essentially, this is a privilege that many across the world could only dream of. The academy is an elite institution. Without understanding the nature of the difficulty of study, and the rigour generally applied to it, those outside are sometimes dismissive of the work of the academy. Likewise, academics, who know themselves to be highly intelligent - another form of hierarchy - can sometimes appear to see themselves as superior to practitioners.

Whilst working as a practitioner, I encountered many academics, as well as others, who approached me with a view to gaining access to participants for their work. In addition, the Traveller Education Service itself was sometimes the object of investigation. At the same time, I had gained my master’s degree, and had begun to make relationships with academics working in the Romani Studies field. I wasn't an academic myself, but I had studied at a relatively high level and the combination of my practice, and my studies meant that I had some ideas of my own.

If I felt comfortable with a researcher's study, and had the time to give it, I did work alongside academics who approached me and, hopefully, in this way, I and my staff team were able to contribute to the developing knowledge in the field. Nevertheless, there were times when I, myself, felt a little taken advantage of, and times also when I felt that what had been written did not accurately reflect the reality of the situation being described. Sometimes, I also found the process of being anonymised unpleasant, depending on the way in which this was done.

I also attended meetings of an academic discussion group operating in the field at the time and, whilst I learnt much from this, this was also, on occasion, an uncomfortable experience. Academics were not my group - my group was my peers in the Traveller Education field - and I was never at the cutting edge of new thinking about Romani Studies. I used to wonder why my peers did not take the Romani Studies module, which offered such a sound grounding in our field of work, but maybe they had more sense than to stray into somebody else's zone. Nevertheless, I made friends in the academic world, learnt more than I ever would have done had I stayed away, and maintained my interest in the theoretical understanding of the world in which I worked.

The position of the researcher

When the funding for many Traveller Education Services in London was cut in 2011, I moved first into work in the generic Special Educational Needs and Disability (SEND) field. The opportunity then arose for me to undertake my current doctoral studies, focusing on health and well-being, with the Roma groups with whom I was very familiar. The SEND work was challenging and important, but I was keen to return to working in my own field and I gave little thought to how I was to position myself in this new role.

After a while, however, a number of factors became clear to me. Doctoral studies are primarily training for young academics who hope to seek employment in a university. My study was about health and well-being, a field that was relatively new to me. A Doctor of Philosophy should know something about philosophy, and a study of the specific needs of a highly racialised collectivity within the structures of the federal state of the European Union, at a time of unprecedented global, social and political turmoil, required some degree of understanding of social theory. I was about halfway through my three-year target time frame before the reality of this struck me.

There were times when I found the sociological lexicon difficult, and occasions when I wondered whether ordinary language could serve the same purpose, but there were clearly new concepts that needed new words to express them. I wondered how people unfamiliar with sociological language would be able to easily read sociological texts and, therefore, how the audience for new understandings might be extended beyond the academic world. This is clearly important for a discipline in which many practitioners see their role as that of supporting political change. Some terminology was familiar to me, and some was new, and I had to do the best I could in the time available.

I was also undertaking my study later in my working life; by no stretch of the imagination could I be described as a young researcher! I was at the beginning of a new career, but I had a wealth of experience of life and work, and of the communities that my study sought to support. I struggled to position myself and it was not easy. The workload was great, the pressure was on, and I had family commitments that were important to me. I envied the young sociologists, who had the tools they needed at their disposal but, at the same time, I knew the value of my many years of practice. How was I to see myself in this new scenario? In the end, I decided to describe myself as a practitioner who also did some academic work.

The MA and the PhD

The topic of my MA dissertation was of my own choosing, but the theme of my PhD study was devised by the university. I was very fortunate in being awarded a scholarship to undertake this study and I see this as the privilege it is. Nevertheless, I somehow had to complete the research to meet the requirements of the work of the university within which it was located whist, at the same time, making it my own. The whole of my master's dissertation was based on my day-to-day experiences, and this brought vibrancy to it, which made writing it feel exciting and creative. Linking what I found in the world to theory was a dynamic and enriching process.

Aspects of the PhD thesis so far have been similar, and the analysis of the data is proving to be the same, but the more formal structure and process of the PhD have made the writing of it sometimes more of a struggle. My hope is to be able to present my work in the formal voice of the researcher whilst, at the same time, including this reflexive section and the opening vignette, so I can retain a flavour of what I bring to the study from my past experience.

In terms of the methods used, these were determined in discussion with my supervisors, but they reflect my own approach to the research. As far as the process of 'decolonizing' Romani Studies is concerned (Matache, 2017), I have academic colleagues who have taken the decision to only undertake research with Gypsy, Roma and Traveller community members that is co-productive (Ryder 2015; Greenfields, 2013; Ryder and Greenfields, 2012). This study is not such a piece of work, but its focus is very much on the voices and views of its Roma participants, and on using its theoretical framework to challenge essentialising notions about Roma people. I hope this will go some way towards redressing the power imbalance.

Dealing with the challenges of the PhD process offers an opportunity for growth and learning at a deep level and its ups and downs are inevitable. This short reflexive piece refers to many complex sites for investigation and even a PhD, long though it seems at the time of writing it, can only start to examine in depth its own one tiny area. Hopefully, I can do mine justice.

Reflexive notes on the methodology and methods

What worked well when carrying out the interviews? What could I have done better? I tried to allow the participants to speak without leading their answers but, sometimes, my previous practical and academic experience made this difficult. It was impossible for me to approach the interview conversations from any position other than the one I already had; all I could do was to try to remain aware of this. I was a white woman in my sixties, a mother, grandmother, and daughter of a very elderly father. I was British, I had spent my whole life in the UK, and I had received a significant amount of education.

I was also aware that my own experiences of using the NHS, for myself and my family, would influence the approach I took to the interviews and the analysis of the findings. In addition, the theoretical position I was using, with which to frame my study, had been chosen on the basis of my previous experiences and understandings, and would also influence my thinking. Although my political position was to support the NHS as a collective resource for the whole UK community, my family's experiences of the services received had been mixed, and I was not entirely enamoured of its highly medicalised and drug-based model. The sudden disruption of all our lives in early 2020, by the global health crisis caused by SARS-CoV-2, generated much-needed respect for the staff of the NHS, which I shared. However, a new valuing of healthcare workers did not invalidate the justification for critique of the influence of economic factors on healthcare models and types of treatment.

All of these factors would, inevitably, have influenced the interview schedule I had devised, as well as the way I approached the participants and the way in which they responded to me. I had read the existing literature about Roma people's health and well-being in the UK, I had volunteered at the charity, working specifically on the Roma mental health project, and I had spent many years working with Roma families in the education system. However, whilst these were my biases, this earlier work meant that I felt comfortable talking to the participants, and my familiarity with their situation may have helped them to feel comfortable speaking to me. This was also aided by the presence of representatives and interpreters whom they already knew, and the interview settings, which were familiar to them.

Listening to the tapes, and reading the transcripts, I found I had sometimes made assumptions during the interviews about what the participants were saying that later seemed to be incorrect. Sometimes, this was to do with communication, and the use of the different languages; sometimes I had just misunderstood. There were also certain points made by the participants that I felt could have been further developed. On the other hand, the knowledge and experience that I brought to the interviews probably helped me to develop other aspects of the conversations and, I hope, to communicate understanding and empathy. I was so used to helping Roma people in a practical way in my previous work that it was hard during some interviews not to want to do this and, on one occasion, it felt wrong to leave without offering practical help. I gave Pansela the details of a local food bank after her interview and relayed this information to the professional who had introduced us, and who worked regularly with Pansela's family.

In relation to my work history, I found interviewing Roma people to be a different way of getting to know them. I had anticipated that the seemingly distant relationship between an academic researcher and their study participants would be less meaningful than the hands-on work I had done in the past. Although I did not know any of the participants beyond the interview situation, other than a brief acquaintance with three people whom I had met at the offices of the charity, over the many months spent listening to the interview recordings, reading the transcripts, and analysing the findings, I felt I got to know the participants in quite an intimate way, and I became very fond of them. Over time, they took on their anonymised names for me, and I sometimes had to check back, to remind myself of who somebody actually was. Some of the participants, particularly, had shared a lot of personal information and almost all had engaged with the interview process with enthusiasm. Without this, the study would have no purpose or meaning. The participants brought this study to life and I very much hoped to be able to do justice to what they offered to the study and to me.

Seeing the struggles and, yet the positivity that the participants brought to their lives in London lay at the heart of both the practical and the theoretical aspects of this study. Noticing and understanding the meanings they made of their experiences and considering these alongside the assumptions that are often made about Roma people, their motivations, and their abilities, became the purpose of my study. In order to reframe the positioning of Roma people by others, and to see them differently and more constructively, a starting point, it seemed to me, was to talk to them, and to give them an opportunity to speak. I was aware, though, of the power imbalance here. In the case of my study, the participants were not equal partners in the research. All I could do was to try to be aware of this, and to write about what they told me as accurately and respectfully as I could, bearing in mind that I was, inevitably, interpreting the data from the position of my own assumptions and understandings.

I was struck by the patience with which the participants faced their situations, quietly adapting to new circumstances, and trying to find ways to make their lives in London work, for themselves and for their children. I was reminded of the very early 1970s, when I first moved to London and lived in North Kensington. The local community there had included many people from the Caribbean, whom I remember as gentle and sad. The anger of African

Caribbean people came later. Talking to the participants about their experiences made me see in a new way how misunderstood Roma people often are and, at the same time, how it might be possible for new narratives to begin to be constructed.

Reflections on the end of the PhD process

Howarth (2015) noted the transitory and changing nature of subjectivity and suggested that the subjectivity of the researcher should be understood in this light, as well as the subjectivities of research participants. My own experience of undertaking and completing the present study could be illustrated by a range of metaphors, all of which describe processes of change. A journey, climbing a mountain, weaving a complex tapestry… In a long and challenging learning process, perhaps the most important change for me has been one of gaining confidence in my own work. By the time the end of this study was in sight, I knew that I had worked hard and struggled through some difficult times, and that I had learnt a great deal. I had learnt about the work of Huub van Baar, whom I believe to be an important scholar in this field; I had learnt about post-structuralist thinking and about the philosophical background to this tradition of thought; I had learnt about the writing process and the need to let go of what did not work; and I had learnt about the Roma participants, each as individuals with something to say. In the process of all this, my confidence grew and, just as I tried to respect and honour the voices of my participants, I began also to find my own voice, and to begin to be able to write what I thought, without constantly censoring it in case 'someone who knew more than me' might think what I said was 'wrong'. I knew more about what I did not know, but I also knew a little more than I had done when I started working on the study. I stopped doubting myself, perhaps a little late in the day but, nevertheless, enough to be able to speak alongside the Roma people whose contributions have enabled this piece of work to exist. In the end, it took much longer than anticipated. Had I known how difficult it was going to be, I might not have done it but now, when it is nearly complete, I'm very glad that I did.

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APPENDICES

Literature search strategy

An early Google search of the Internet, on 24th August 2015, for ‘health of Roma communities in UK’, produced 1,090,000 results and a number of key documents from this search formed the basis of the proposal for the study. Initially, for the purpose of preparing the project proposal, the first twenty items were examined and eleven of these were cited, with the addition of a report on the gathering of ethnicity data for health research in the UK (Mathur et al., 2013), and some historical context sourced from a definitive book (Hancock, 2002).

The initial Google search was followed by a systematic review of relevant academic, peer-reviewed literature, using EBSCOhost, the online research service offering access to the following Health Science Research Databases: Academic Search Premier, MEDLINE, Psychology and Behavioural Sciences Collection, PsychINFO, SPORTDiscus and CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature). The University of Greenwich Library Search facility was also accessed, and Google was used to locate European Union reports and directives, as well as known items not accessible through the library-based facilities.

The key search terms used were: Roma, health, well-being, United Kingdom.
Secondary terms used were: Gypsy, Traveller, Romani.
In addition, the following terms were used: policy, European Union, England, Scotland, Wales, Northern Ireland.

The time frame used was between 2000 and 2016, although some earlier items were included, where their content related directly to the findings. Relevant documents published subsequently were added to the literature review as the study progressed.

Further to the searches for academic, peer-reviewed articles, reference lists and citations of key papers and books were examined, along with references cited in presentations attended. A media search and a search of key authors were also carried out, all with the intention of identifying additional relevant texts.

The outcomes of each search for peer-reviewed papers were recorded on a table, indicating search terms used, date of search, site searched, the total number of results and number of results relevant to the study. Items were recorded as relevant, if they had relevance to the study as a whole, even though, in some cases, they were not directly relevant to the focus of that specific search.

A large number of papers identified within the search results were discarded, for one or more of the following reasons: the paper referred to an unrelated topic, ‘Roma’ referred to the capital city of Italy, ‘Roma’ or ‘Romani’ referred to the first or family name of the researcher, the paper was a duplicate, the paper was in a language other than English.

In order to eliminate double counting, and to separate them into focused groups, papers identified as relevant to the study were listed under the following categories:

- Health and well-being needs of Roma communities in the UK
- Health and well-being needs of Roma communities in Europe
- Health and well-being needs of Gypsies and Travellers in the UK
- Roma health and well-being policy in each of the four nations of the UK

The total number of peer-reviewed papers initially identified, relevant to the study, was 102. These articles were stored, and their abstracts were printed and examined. Of these 102 articles, a further 8 were found to be duplicates, 3 were on unrelated subjects, 39 focused on Roma policy and inclusion within the EU but without reference to the UK, and 5 articles specifically looked at policy relating to Gypsies and Travellers in the UK without reference to the Roma.

The remaining 47 papers were then organised by category, as follows:

- Health and well-being needs of Roma communities in the UK - 2
- Health and well-being needs of Roma communities in Europe - 21
- Health and well-being needs of Gypsies and Travellers in the UK - 20
- Roma health and well-being policy in each of the four nations of the UK – 4

In addition, 63 further items were identified for citation in the literature review. These comprised;

- Additional academic articles – 25
- Academic presentations – 1
- Books – 2
- EU/European reports and directives – 7
- UK Government/local authority reports and presentations – 2
- NGO reports and guidelines – 14
- Solicitors’ reports - 1
- Media articles and programmes – 5
- Websites – 6

These additional 58 items were categorised as follows:

- Health and well-being needs of Roma communities in the UK - 27
- Health and well-being needs of Roma communities in Europe – 7
- Health and well-being needs of Gypsies and Travellers in the UK – 0
- Roma trafficking and child sexual abuse in the UK – 4

- Roma health literature reviews – 3
- Roma in the UK, other than health – 2
- Roma data collection by ethnicity in the UK - 3
- National Roma Integration Strategy (NRIS) in the UK – 5
- NRIS, Roma Inclusion and Human Rights in Europe – 6
- Other topics – 6

Papers relating to the health and well-being needs of Roma communities in the UK were analysed, along with studies and documents relating to EU healthcare policy with regard to Roma communities, where these contained specific reference to the UK.

As well as the interrelationships between these themes, directly in terms of the Roma communities living in the UK, there was cross-over with regard to the needs of long-standing UK Gypsy and Traveller communities and, also, Roma communities in other European countries. However, papers relating to UK Gypsy and Traveller communities and to Roma communities in other European countries were not analysed unless they contained specific information about the health and well-being of Roma community members within the UK.

ROMA HEALTH AND WELL-BEING UK - KEY PAPERS

	TITLE	AIM/RESEARCH QUESTION	THEORY/ EPISTEMOLOGY	METHODS	RESULTS/ REPORTED FINDINGS	SUB-THEMES	STRENGTHS AND LIMITATIONS
	ROMA VOICE INCLUDED - UK						
1	Marsh, A. (2017), *Stories of Health & Wellness amongst Romani and Traveller Communities in Wales*, Cardiff, Romani Cultural & Arts Company.	**GRT health, Wales** ‘The aim of this project has been to explore the health experiences of Romani and Traveller families, specifically in relation to early childhood, in order to understand their perspective around accessing health services and provision, capturing their experiences through storytelling...’ (Marsh, 2017: 3).	**Participatory Action Research**	**Qualitative** study, using organic process of developing project from ‘inside out’, with community participants, health practitioners and professionals as co-creators. Incorporated principles of participatory action research (PAR) **Semi-structured interviews with individuals and groups** of younger parents, older parents and carers Participants were self-selecting and were involved in the choice of topics discussed. 107 interviews carried out by six **community facilitators and researchers**	Key findings included: **differences** in health and wellness experiences **across provision and across the country**; positive experiences with health visitors in building trust and confidence; higher use of accident and emergency services than among the general population; hospital visits by large groups of relatives as an area of potential misunderstanding; reported good practice and a general trust and appreciation of local doctors; a tendency for dental services to be avoided; and **knowledge about availability of healthcare provision** to be **rarely available in languages or forms accessible to the participants.** **Stresses the need for reliable data.**	**Lack of data** **Differential experiences** **Lack of accessibility**	**Only study to consider Roma in Wales –** supported by NHS Wales Centre for Equality and Human Rights. **Positive community-based approach suggests capture of GRT experience,** although views of GRT participants and those of professionals not differentiated Slovak Roma participants included, but number not specified, so **not possible to know specifically the views of the Roma** Breakdown of characteristics of participants not given numerically, or in terms of the findings, so **no specific data on Roma people** Some input from younger children, but no detail given

							Uses only one direct participant quote Participants were self-selecting and were involved in the choice of topics discussed – therefore, **findings may be biased and not easily generalisable** Refers to **poor living conditions, centuries of poor diet, poverty, environmental degradation and high levels of toxicity in countries of origin** as negatively impacting on Roma health outcomes. Also **notes European Commission proceedings against Slovakia and Czech Republic** regarding discrimination and exclusion from education and health services. **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020).
2	Newton, P. and Smith, D. (2017), 'Factors influencing uptake of measles, mumps and rubella	**GRT health, Kent, UK – MMR immunisation uptake**	**Not stated, although 2016 paper, based on the same research,**	**Cross-sectional qualitative study**	**Structural effects found to be more important than access to immunisation**	**Structural effects take precedence over**	A small, self-selecting sample, so **findings may**

	(MMR) immunisation in site-dwelling Gypsy, Roma and Traveller (G&T) communities: a qualitative study of G&T parents' beliefs and experiences', *Child: Care, Health and Development*, Volume 43, Issue 4, 7th March 2017: 504-510.	'...the...study explored: 1 experiences and beliefs about childhood immunization; 2 Beliefs about the risks of immunization and non-immunization; 3 Perceptions of obstacles to, and facilitators of, immunization; 4 Views on increasing participation in immunization programmes' (Newton and Smith, 2017: 2).	**states a critical realist framework**	Purposive sampling **Five focus groups** with 16 site-dwelling Gypsy and Traveller women with pre-school aged children, conducted by two female community members (one, a health worker) Topic guide for focus group developed following pilot survey **Thematic analysis**	**services and cultural attitudes.** Although these influenced MMR uptake, more important effects were the result of the organisation of healthcare services, poor accommodation standards and widespread racism and discrimination. The effects of these inequalities worsened existing barriers to immunisation services. Findings support earlier studies suggesting access to health services impacts on immunisation but is mainly the result of a poor fit between healthcare delivery and nomadic lifestyles.	**accessibility and culture**	**not be generalisable**. **Three participants identified as European Roma. This is a small number, so results not generalisable to all Roma people.** Also, site-dwelling Roma are unusual so, again, not necessarily representative. Direct **quotations** are given, but those **from Roma participants are not identifiable**. Findings from focus groups, therefore, **a consensus view from participants from three distinct groups (GRT)**. Looks at barriers within the health system for the Gypsy and Traveller (particularly, nomadic) population, rather than barriers experienced by all service users. Therefore, **similarities and differences between GRT and other groups are not identified**. **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the

							NRIS (2011 – 2020).
3	Warwick-Booth, L., Trigwell, J., Kinsella, K., Jeffreys, K., Sankar, D. and Dolezalova, M. (2017), 'Health within the Leeds Migrant Roma Community; An Exploration of Health Status and Needs within One UK Area', *Health*, 2017, 9: 669-684.	**Roma health, Leeds, UK** 'This study explored the health status and associated health needs of the Leeds Roma migrant community, a hard to reach and under-explored group across Europe' (Warwick-Booth et al., 2017: 669).	**Not stated**	**Mixed methods** **Focus groups and questionnaires with Roma community members** Data collection undertaken by Roma bilingual advocate and Roma volunteers **Interviews with local health professionals**	**Gap in academic evidence base on Roma health needs** **Lack of monitoring by ethnicity data** **Poorer health closely linked to wider social determinants of health** – health interventions should take account of **complex influencing factors** **Language barriers** **Findings should inform strategies** to tackle health inequalities and promote health within Roma communities	**Limited research** **Lack of monitoring** **Social determinants of health – complex influencing factors** **Language barriers** **Lack of strategy**	**Different methods used** with Roma participants and health professionals **could affect accuracy of findings** Short, locally focused paper, whose **conclusions can be applied much more broadly** **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020) despite recommendation for strategies to tackle health inequalities. (References the NRIS but not in terms of interventions or strategy)
4	Brown, P., Allen, D., Czureja, S., Dinu, L., Glowacki, S., Hesk, G., Ingmire, S., Martin, P., Orsos, O., Palmai, M. and Rostas, T. (2016), *Supporting Roma Voices*, Manchester, Sustainable Housing and Urban Studies Unit, University of Salford.	**Roma settlement and life in the UK – Includes Roma health within wider brief** **Glasgow, Leicester, London, Oldham, Salford, Sheffield** The following issues were explored: 'The settlement and integration experiences of Roma migrants	**Not stated, although a participatory approach was taken**	**Focus groups** – semi-structured question guide devised by the researchers (not included in the report) **Paid and trained Roma community advocates** in 6 UK locations – two-year project **Thematic analysis**, using NVivo software, and with **community**	**Healthcare findings**: Experiences contextualised by those in countries of origin Feared discrimination did not always occur Poor experiences with UK healthcare regularly reported, often linked to **language barriers**	**Impact of, and comparison with, experiences in country of origin** **Language barriers, lack of knowledge and misunderstandings within UK health system**	**Focus on Roma voice**, including short section on health experiences Practitioner voice not included Positive involvement of Roma community members **Focus groups, so consensus view**

		living in areas across the UK The specific areas of community relations, housing, education, employment and social welfare and their role in settlement in the UK The provision of knowledge that would enable local authorities and other services to enhance the settlement experience of Roma migrants now and in the future’ (Brown et al., 2016: v).		**advocates involved in the analysis**	Lack of knowledge about UK health system, sometimes leading to misunderstandings Some spoke highly of services received, often in comparison to those in country of origin, or benefiting from low-cost medicine		Healthcare services explored within context of overall UK service provision; therefore, not explored in great depth Refers to European documentation on Roma migration, employment and education **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020).
5	Smith, D. and Newton, P. (2016), ‘Structural barriers to measles, mumps and rubella (MMR) immunisation uptake in Gypsy, Roma and Traveller communities in the United Kingdom’, *Critical Public Health*, Volume 27, 2017, Issue 2: 238-247.	**GRT health, Kent, UK – MMR immunisation uptake** ‘This [critical realist] perspective is applied to explore the issues GRT parents consider when making choices about immunisation, contextual issues such as the healthcare system and the relationship to underlying social structures...’ (Smith and Newton, 2016: 3).	**Critical realist framework**	(As for Newton and Smith, 2017) **Cross-sectional qualitative study** Purposive sampling **Five focus groups** with 16 site-dwelling Gypsy and Traveller women with pre-school aged children, conducted by two female community members (one, a health worker) Topic guide for focus group	Findings indicate that **attitudes towards MMR result from adaptive and strategic responses to deeper structural factors**, such as high unemployment levels, economic inactivity, poverty, poor living conditions and social and spatial exclusion, **rather than to cultural values**.	**Impact of structural factors, rather than of cultural values**	A small, self-selecting sample, so **findings may not be generalisable**. **Three participants identified as European Roma. This is a small number, so results not generalisable to all Roma people.** Also, site-dwelling Roma are unusual so, again, not necessarily representative. Findings from focus groups, therefore, **a consensus view from participants**

				developed following pilot survey **Thematic analysis**			**from three distinct groups (GRT).** This study **does not differentiate between the responses of Roma and members of the other groups included.** It is also likely that the two **community members who conducted the focus groups** were from the non-Roma communities and **may, therefore, not have been specifically attuned to the three Roma participants.** It is, therefore, **not possible to know whether the emphasis on structural factors applies equally to all three groups within the cohort, including the Roma group.** **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020).
6	Willis, L. (September 2016), *Slovak Roma Health Needs Assessment*, Sheffield, Public Health Intelligence, Policy Performance & Communications, Sheffield City Council.	**Slovak Roma health needs assessment, Sheffield** 'Purpose: To gather information about the needs of recently arrived Roma groups;	Uses '...**a social view of the determinants of health inequalities**... (Willis, 2016: 56).	**Detailed literature review**, including the social determinants of health inequalities in Slovakia; **qualitative interviews and group discussions from perspectives of service providers and Roma residents** (group and individual interviews with over	**Multiple, multi-faceted health needs**, spanning many areas of life and closely linked to history of exclusion and deprivation in Slovakia. **Survival needs ahead of improving physical activity and diet**; **language barriers**;	**Multiple health needs but primary focus on survival** **Language barriers** **Lack of data**	**Very comprehensive study of health needs of Slovak Roma people in Sheffield** - focused on medical issues but within the social context of Roma people's lives in Slovakia and Sheffield (**the social determinants of**

		To better understand the health needs and behaviours of this group in comparison with non-Roma patient groups so services can be designed to meet their needs in an effective and efficient manner; To promote better sharing of intelligence and collaboration between agencies and service providers; To identify interventions which require additional resources from central government and European structural and investment funding to promote Roma inclusion in light of recent migration trends and the extreme deprivation of this community; To support the development of business cases for a series of community development interventions within the communities under analysis' (Willis, 2016: 5).		40 service providers;10 exploratory interviews with Roma individuals, undertaken in English; **5 interviewees subsequently trained as community researchers**, who assisted with developing the interview template and conducted 30 interviews in their own community **using mostly the Romani language, Romanes** – age range young adult to over 50).	**lack of accurate data and need for systematic responses** to evaluations of Roma health needs; **aspiration within the Roma community**, despite its many needs. **Recommends holistic responses** within Sheffield, **involving the Roma** community.	**Lack of systematic response** **Need for community involvement**	**health**). The health needs of other Roma groups may differ. **Acknowledges availability of European structural and investment funding for Roma communities, in particular, for mediation.** Slovak Roma people and service providers interviewed, but not directly quoted. **Positive involvement of Roma community members in the fieldwork, although this could bias the findings.**
7	Roma Support Group (2015), *Access to Health*	**Access to health services for Roma community**	**Not stated**	**Survey questionnaire** approved by	**Barriers identified by participants** in accessing GP services:	**Language barriers, some caused**	**Roma service users quoted**, in relation to their

	Services for Roma Community Members in L.B. Newham, London, Roma Support Group.	**members in Newham, Northeast London** Project undertaken by Roma Support Group, seeking to engage Newham CCG in understanding barriers to accessing primary health services experienced by Roma patients Part of **ongoing work** by the RSG, **to promote positive engagement between local healthcare practitioners and Roma patients**		Newham CCG, completed by Roma community members, patients of local GP clinics/RSG service users, translated into Polish, Slovak and Romanian	Language barrier - difficulty booking appointment with an interpreter Lack of health advocacy and interpreting service Long wait **Exclusion from health services**; in particular, regarding gynaecological illnesses, sexual health, family planning and mental health, **when it is inappropriate for family members,** often children, **to act as interpreters** Closure of local Bi-lingual Health Advocacy Service found to lead to overreliance on A&E Effectiveness of Health Advocates, who understood Roma culture, **cultural taboos and the discrimination and disadvantage faced by Roma people**	**by structural changes to local provision** **Cultural barriers** **Discrimination faced by Roma needs to be understood** within health services - advocates seen as successful here	experiences of specific local healthcare practices – **findings shared with service providers** Newham CCG suggested findings could lead to introduction of pilot projects in GP clinics mostly used by Roma and, later, in other local health practices Practitioner voice not included A positive and proactive project, which allowed plenty of space for the views of Roma clients to be heard, who had not been consulted previously It is not known what the long-term outcomes of this work have been
8	McNulty, A. (June 2014), *Health Needs Assessment: Exploration of the health needs of people who have arrived in Newcastle upon Tyne from central and eastern European countries*, Newcastle upon Tyne, Health and Race Equality Forum, Newcastle Council for Voluntary Service.	**Health needs assessment** commissioned by Newcastle upon Tyne public health team '…to inform service development and reduce inequalities' (McNulty, 2014: 3). Includes Roma participants	**Not stated**	Background information **uses local data and wider literature** 73 individual accounts: **45 people from Poland, Czech Republic and Slovakia – group discussions and**	Background information: Stresses **social determinants of health** and **structural barriers** to good health ***for migrant people generally***; **language barriers *for all***; **lack of information about the NHS *for all***	**Social determinants of health/structural barriers, leading to stress** **Barriers to access *for all newly arrived migrant communities***	Study initiated by local health authority, showing **positive wish to improve services – does not single out the Roma on the basis of culture** **Roma participants included but number and demographics not stated**, so some

				interviews – age range 16 to 50s **28 practitioners** shared experience of working with people from Poland, Czech Republic, Slovakia and Romania, across a range of service provision – method not stated Warns against constructing ‘a single story’ about any group of people (citing Adichie in 2009)	Findings relating to Roma: **Poor quality accommodation** among Czech and Slovak Roma; **low uptake of sexual health information and services**; **low uptake of antenatal and maternity care**; some Roma said **they no longer feel like migrants**; economic, **social and cultural diversity within Roma communities**; complex issues of **discrimination** in countries of origin impact on opportunities following migration; **stress**, relating to difficulties in accessing good accommodation and jobs	**Diversity amongst Roma communities**	outcomes specific to Roma cannot be determined Findings not always differentiated between people from Central and Eastern Europe and practitioners, so **not always clear whose view is being expressed** However, like Tobi et al., 2010, **offers comparison with other migrant communities**, whose experiences are often very similar – **a necessary caution against stereotyping** of any **community and against constructing the Roma as, automatically, a special case**
9	Roma Support Group (2012), *Roma Mental Health Advocacy Project: Evaluation Report*, London, Roma Support Group.	**Evaluation report of Roma mental health advocacy project in Northeast London** **Aims:** ‘Improved access to mental health services for Roma community members, as well as an increase in the level of their satisfaction with mental health services; Improved well-being and empowerment of Roma service	**Realist Evaluation** (context of change, mechanisms to produce change and outcomes to measure change) **combined with Participatory Evaluation** (co-design and community engagement) External evaluation was not used. The researchers evaluated the project themselves, with the aid of an external evaluation consultant acting as ‘critical friend’.	**A range of data collection methods, consistent with the chosen theoretical approaches** Mixed methods – **focus group meetings**; entry form; service users’ action plans; distance-travelled form; case notes; case records; observation notes; minutes of meetings; **one-to-one interviews**; feedback forms; verbal feedback	**Recommendations:** A model of work focusing on: ‘[I]mproving communication strategies with Roma mental health service users; [p]erson-centred care; [a] holistic approach that combines individual and social empowerment; [a] holistic approach that supports individuals to improve other aspects of their lives that [affect] mental health such as housing, welfare etc.; and [r]esearch to explore the impact of racism and discrimination on the mental health of the Roma’ (Roma	**Need for improved communication strategies and holistic approach** **Need for research on impact of racism and discrimination on mental health of Roma** **Reoccurring non-effectiveness of mental health treatments**	Limited background information on previous research into Roma health and well-being needs but, **seemingly, a seminal project**. Locates Roma mental health difficulties within context of traumatic life events, marginalisation, exclusion, cultural stigma, and lack of trust in Eastern European medical services. **Does not discuss EU intervention programmes** (e.g. The Decade of

		users with mental health needs; Raised awareness of Roma culture and Roma patients' specific needs amongst mental health service providers' (Roma Support Group, 2012: 5). **Research Questions:** '1. What is the socio-cultural profile of the Roma service user wishing to access mental health services? 2. How does the relationship between client (Roma service user) and mental health advocate and its dynamics effect empowerment of the client? 3. What type of cultural information is given to mental health professionals by the advocates in the process of their mental health advocacy support and how does it change their knowledge?' (Roma Support Group, 2012: 6).			Support Group, 2012: 7). Notes **the reoccurring non-effectiveness of mental health treatments, in particular CBT**.		Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020). Project evaluated by researchers, with external consultant, so **evaluation outcomes could be biased towards requirements of the funders**. Roma service users' responses collated, and data presented in verbal and numerical forms - a very small number of quotations One example of feedback from service provider, regarding use of information leaflet produced by the Roma Support Group
10	Tobi, P., Sheridan, K. and Lais, S. (2010), *Health and Social Care Needs Assessment of Eastern European (including Roma)*	**London -** **Participants from four Eastern European communities –** Polish, Lithuanian,	**Not stated**	Quantitative and qualitative (**mixed methods**, stated as the standard research strategy in migration studies)	Identified Roma health issues: diabetes, depression, asthma, cancer, TB, heart problems	**Social determinants, including poverty, racism and discriminatio**	Study undertaken in London Focus groups used with Roma respondents,

	individuals living in Barking and Dagenham: Final Report, London, Institute for Health and Human Development, University of East London.	Albanian (**including** Kosovan) and **Roma**, commissioned by NHS Barking and Dagenham **Key objectives**: To obtain best estimates and projections of the population of Eastern European nationals living in the borough from a review of existing intelligence To understand their particular health and social care needs To estimate the future demand for services		**Document and data review**; World café with Albanian/Kosovan group; **Focus groups with Roma communities: one for Polish Roma, one for Romanian Roma;** one-to-one interviews with Polish and Lithuanian communities; questionnaire survey (included health behaviour and access to healthcare – questionnaire not included in the report) Thematic analysis of qualitative data; survey data analysed with SPSS, using Epidata	Illness amongst Roma in Barking and Dagenham often related to poor working and living conditions and poor diet Roma respondents reported community members dying young; mental health and disability as taboo subjects Homosexuality identified as taboo amongst Roma and Albanians/Kosovans Access to services hindered by language issues Literature review findings: Mental health issues identified for Albanian and Roma people in the health literature (not referenced). Racism and discrimination run throughout Roma health issues (not referenced). Bulgaria and Romania lag behind EU averages for mortality and morbidity rates (not referenced).	**n linked to poor health** **Cultural barriers** **Language barriers** **Not all identified issues are Roma-specific**	therefore a consensus view, rather than individual Helpful comparison with other Eastern European communities in same location Mixed methods give broader picture Findings clearly presented Roma voice – yes Practitioner voice - no States that Roma included as known to suffer disproportionately suffer worse health and social inequalities, but **this assertion is not referenced**. **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020).
11	Fremlová, L. (August 2009), *The movement of Roma from new EU Member States: A mapping survey of A2 and A8 Roma in*	**England** - Primary focus - to explore school provision for A2 and A8 Roma children in England	**Not stated**	**Literature review**; information gathered from NGOs; two **questionnaires** – one for local	**Limited research** looking at Roma from A2 and A8 countries **Negative stereotyping** reported by respondents **towards**	**Limited research** **Lack of data**	**Detailed, committed study**, using mixed methods to give **broad picture**

	England, London, European Dialogue.	**Includes Roma health within wider brief**		authorities, one for Roma respondents; **face-to-face interviews with Roma representatives**, and with statutory and non-statutory practitioners working with Roma; **national event** held at end of study to exchange experience and expertise	**East European migrant identities, rather than towards Roma identities** **Failure of** most **Central and East European governments to implement national policies** to protect Roma Some respondents returned home for care in the areas of gynaecology, cancer treatment and hospital care Long waits for appointments, **perceived inadequate quality of services** and **language barriers** identified Health and well-being of children negatively affected by confusion regarding entitlement to state support (for parents in or out of work) However, **clear majority happy with healthcare in UK, due to lack of discriminatory treatment** **Lack of ethnically disaggregated data** on Roma **Lack of coherent policy** on Roma at local and national level Confusion at local level regarding rights	**Poor quality services and language barriers** **Lack of coherent policy** **Structural factors, including poverty** **impacting on health** **UK services positively experienced due to lack of discrimination**	**Not always user-friendl**y due to lengthy descriptive passages No information provided as to who Roma ‘representatives’ were, or who they represented **Roma consulted about healthcare but not directly quoted**, although practitioners directly quoted – gives an unbalanced picture Study **situated in context of European Free Movement Directive (2004) and failure to protect Roma from discrimination** in Central and Eastern European countries. **Does not discuss EU intervention programmes** (e.g., The Decade of Roma Inclusion (2005 – 2015).

					and entitlements, can lead to **hardship and poverty, threatening well-being of parents and children**		
12	Fremlová, L. and Ureche, H. (Autumn 2009), *New Roma communities in England: A strategic guide for directors and senior management*, London, European Dialogue.	**England - Strategic guide** for local authority senior management, to support service provision for newly arrived Roma communities in England Offshoot pamphlet from study by Fremlová, 2009 - A2 and A8 Roma – **Includes Roma health within wider brief**	**Not stated**	**Guidance drawn from study by Fremlová, 2009**	**Need for coherent policy** and identified, responsible staff in every local authority **Need for information and advice for Roma people and practitioners**, **and training** for all practitioners and elected officers **Need for adequate resources** to address needs of Roma people, including healthcare issues Some respondents returned home for care in the areas of gynaecology, cancer treatment and hospital care Long waits for appointments, **perceived inadequate quality of services** and **language barriers** identified However, **majority happy** with healthcare in UK, **due to lack of discriminatory treatment**	**Lack of coherent policy** **Need for advice, resources and training** **Perceived inadequate quality of services** and **language barriers** **Lack of discriminatory treatment overrides other concerns**	**Positive, practical outcome** of the study by Fremlová, 2009 **No follow-up work** published to assess the effectiveness of this booklet **Roma consulted about healthcare but not directly quoted**, although practitioners directly quoted – gives an unbalanced picture **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion.
13	Clark, C.R. (28th April 2014), 'Glasgow's Ellis Island? The integration and	**Roma in Govanhill, Glasgow – includes health**	**Intersectional approach, with**	**Ethnography, using '...an intersectional approach to viewing, locating**	**Integrative cultural exchanges** as a fact of life, **countering**	**Intercultural exchanges counter**	**Unusually strong on theory** and suggests the use of

	stigmatisation of Govanhill's Roma population', *People, Place and Policy*, 2014, Volume 8, Issue 1: 34-50.		**reference to feminist theory** **Microsociological and ethnographic approach, within wider European and UK political and policy context** Notes that intersectionality raises further epistemological and ontological questions **Notes the limitations of research with GRT communities tending to be seen through '...a highly racialised and/or ethicised lens...' (Clark, 2014: 3).**	**and understanding power'** (Clark, 2014: 3).	**stigmatising narratives** **Complex power dynamics** central to understanding how **structure** interacts with **agency** Main issues facing Roma communities in Govanhill similar to those facing other migrant communities as recent arrivals, including health needs Low GP registrations and immunisation take- up The author suggests an updated **national and local integration strategy**, modelled on the Beveridge report of 1942, with equality, human rights and multiculturalism at its heart.	**stigmatising narratives** **Complex power dynamics linked to structure and agency** **Issues facing Roma similar to those facing other recently arrived migrant communities** **Need for national and local integration strategy**	intersectionality to widen research perspectives beyond a focus on ethnicity **Lack of clarity regarding the actual fieldwork undertaken and the health 'findings' appear to be drawn from other studies** Suggests greater complexity of interaction between Roma and non-Roma people in Govanhill, in contrast to an assumed division between recently arrived Roma and community members of longer standing, and a positive slant on individual agency. However, a **lack of clear methods and fieldwork findings** mean that this assertion is not evidenced. The study is located within the wider European and UK context and considers **'...the position of Roma struggles for self-determination, identity and equality in contemporary European contexts'** (Clark, 2014: 3). **Does not discuss EU intervention programmes** (e.g. The Decade of

							Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020).
	PRACTITIONER VOICE ONLY – UK						
14	Performance and Research Team, Sheffield City Council. (Updated October 2015), Sheffield Community Knowledge Profiles: Roma Community 2014, Sheffield, Sheffield City Council.	**Roma survey, Sheffield, Yorkshire – includes health** Desk-based, focused on local Slovak and Czech Roma communities	**Not stated**	Not stated – **desk-based research**	Information given is based on **information given by health professionals and practitioners** within the NHS, 2011, for **Slovak Roma people**: **Hepatitis A, B and C; tuberculosis; impetigo.** **Diabetes mellitus; coronary heart disease; obesity; teenage pregnancy; nutritional deficiencies; neonatal health issues relating to consanguinity; childhood anaemia; cultural issues relating to healthcare and homeopathy.** **Lack of health education for Slovak Roma community; high A & E use, often unnecessary; UK appointment-based system a barrier; limited translation services.** **Hearing loss an issue amongst Roma children.**	**Wide range of health issues identified by practitioners** **Language barriers** **Lack of health education for Roma** **Hearing loss among Roma children**	**No primary research undertaken**, so all information is based on the work of others. Information relates to Slovak Roma community in Sheffield only, so **not necessarily generalisable** to other Roma groups. **Mixes local findings with global**, regarding life expectancy and infant mortality, so not comparable. **Does not discuss EU intervention programmes** (e.g. The Decade of Roma Inclusion (2005 – 2015), the NRIS (2011 – 2020). An introduction for people working with local Roma communities, which has been followed in Sheffield by much more detailed studies (Willis, 2016).
15	The Social Marketing Gateway (26th September 2013), *Mapping the Roma Community in Scotland*, The Social Marketing Gateway.	**Roma community in Scotland** - mapping report – **includes health** in wider brief Aims:	**Not stated**	**Mixed methods**: National **online consultation** with 32 Council areas in Scotland - **semi-**	**Findings regarding health**: Pressure on health and social care providers Families in crisis	**Complex health needs** **Pressure on services**	**Unclear as to who commissioned this study** – refers to Brown et al., 2013 but does not clarify its

		'Ensure that Scotland is recognised at European levels for playing an active part in meeting the European Commission's Roma inclusion objectives Build an understanding of the Roma population living in Scotland Increase knowledge about the individual and institutional capacity that exists in Scotland to apply EU funds for the social and economic inclusion/integration of the Roma populations' (The Social Marketing Gateway, 2013: 4). Notes similar mapping exercise looking at Roma across all UK (Brown et al., 2013)		**structured questionnaire** **Telephone or face-to-face interviews** with survey participants **Workshop sessions** **Focus groups with service providers** Use of **literature sources** Direct **engagement with Roma via focus groups, commissioned by Glasgow City Council** (read in conjunction with the mapping report)	Roma returning to Romania to access healthcare services Negative impact of mobility on healthcare provision Roma health inequalities similar to those of Gypsies and Travellers in UK, e.g., **diabetes** and **heart disease** **Obesity** and **alcohol use** significant across Roma population **Women's health an area of concern, due to cultural taboos** Growing confidence among Slovak Roma in using GP practices **Complex emerging health needs** Programme to **increase Roma understanding of health issues and importance of preventative care** **Importance of education**	**Families in crisis** **Identified health issues could be linked to lifestyle** **Cultural barriers** **Need for health education, leading to preventative care** **Active participation of Roma is required**	connection to this report This study **places the situation of the Roma in Scotland firmly within the context of EU requirements for Member States to promote social inclusion of Roma populations** and states that '([t]he EU believes **Member States have the primary responsibility and the competences** to change the situation of marginalised populations...' (The Social Marketing Gateway, 2013: 10). **Notes the importance of education** within the section on health
16	Migration Yorkshire (2012), *Improving the health of Roma communities in the Yorkshire and Humber Region: a guide to good practice*, Leeds, Roma SOURCE.	**Guide to good practice** for health services - **Yorkshire and Humber, UK** Funded by European Commission 'Fundamental Rights and Citizenship Programme'	**No primary research; no theoretical position or methodology stated**	Examples selected from local, national and European activities, demonstrating good practice **Background sourced from European reports** **References the EU Framework for National Roma Integration Strategies, 2011**, within which gap in health status between Roma and non-Roma population is an area for action Notes the **social determinants of health** impacting on the Roma	**Summary of findings** - what works in Roma health: **Active participation of Roma people** Involvement of the voluntary sector Aiming for the mainstream Awareness of the **gender dimension** **Involvement of regional and local authorities** Notes that **these findings reflect general policy approaches**	**Active participation of Roma** **Gender dimension** **Need for regional and local policy** **Findings reflect EU policy recommendations**	Very constructive guide, offering positive ways of supporting Roma people around health The background section contains 'facts' about Roma life expectancy and child mortality rates, citing the European Commission, 2011, but these 'statistics' are drawn from Braham, 1993, and were not evidenced.

				Cites **examples of best practice** from: Roma SOURCE health champion pilot, Sheffield Leeds Roma Health Needs Assessment NHS Newham Pacesetters Mediation Centres in Health Services	**recommended by the Council of the European Union Conclusions on the Inclusion of Roma, 2009**		
17	Poole, L. and Adamson, K. (2008), *Report on the Situation of the Roma in Govanhill, Glasgow*, Glasgow, University of the West of Scotland.	**Roma community in Govanhill, Glasgow, Scotland - includes access to health services**	**Theoretical position/epistemology not stated**	Research builds on report by Adamova, M., Jeffery, S. and Zelmanova, L. (2007) looking at Slovak Roma in Govanhill **Qualitative** research **Notes need for quantitative data** on A8 migrants in Scotland Roma **Semi-structured interviews with key service providers** - not tape recorded, at request of support workers, who were interviewed first, which set the pattern. Notes taken by two researchers. **Open ended questions.** **Slovak Roma not interviewed** '...due to language barriers and the absence of trusting relationships between the researchers and would-be respondents' (Poole and Adamson, 2008: 49). **Support workers at drop-in centre deemed to have significant knowledge** of what worked for the Roma community.	**Findings regarding health**: **Language and cultural barriers** However, what are seen as cultural barriers may sometimes be **misunderstandings** due to differing healthcare systems in the UK and in countries of origin. Specific concerns of GP practices regarding missed appointments and/or missed child immunisations. **Seen as wasted resources and threat to public immunisation programmes.** Growing levels of **malnutrition amongst children**, **overcrowding and infestation** - all **viewed as significant public health risks.** The risks to the Roma are not noted. **Issues of responsibility** - Roma mothers and healthcare professionals. Pressure on community healthcare services, which engage in providing focused support for Roma - seen as relying on 'voluntary' input and	**Language and cultural barriers** **Misunderstandings due to differing healthcare systems in countries of origin and UK** **Perception of wasted resources and threat to public immunisation programmes** **Malnutrition amongst children, overcrowding and infestation viewed as significant public health risks** **Issues of responsibility** **Pressure on healthcare services and Roma seen as a burden**	Very detailed contextual overview given, with emphasis on the significance of discourse. **Refers to the Decade of Roma Inclusion (2005 – 2015)** but **predates the NRIS, 2011** **Can support workers speak for/ represent the views of Roma people?** This research was developed from a study undertaken by non-Roma, two of whom were Slovak support workers. This could have led to **possible bias**, prior to the current study. In addition, this study **does not include the Roma voice**, basing its findings on the views of service providers only. Again, this **may give an incomplete picture**. Nevertheless, does give very interesting picture of **points of view of service**

					goodwill, in the context of overstretched health services. ‘Sharing of the load’ (Poole and Adamson, 2008: 63) - **Roma seen as a burden**. Positive input attracted more work. Practice managers considering closing of lists, to protect quality of service for all registered patients. **General findings**: Problems stemming from **deliberate exclusion** from citizenship **in EU countries**; As a result of **deep-rooted institutional and societal racism**; More should be done to **protect Roma rights in these countries**; **Inconsistent application of intra-EU migration rules** compounds exclusion following migration; **Disproportionate effect of these rules on Roma**, Europe-wide; Recognition of problems faced by Roma increasing - **political solutions to barriers needed**; **Roma have fewer rights than other EU migrants**; This is **legally unsustainable**, within context of EU human rights and anti-discrimination legislation.	**Problems relating to the Roma seen as stemming from institutional and societal racism in EU countries** **Need to protect Roma rights** **Inconsistent application of intra-EU migration rules and disproportionate effect of these rules on Roma** **Need for political solutions**	**providers, in the context of NHS funding crisis and EU requirements**

18	Roma Support Group (2017), *Awareness Training Programme for NHS staff: Working with Roma in Health and Safeguarding Context – Evaluation Report August 2016 – March 2017*, London, Roma Support Group.	**Awareness training evaluation report** - Roma health and safeguarding **Training for health professionals** in Newham, Northeast London **Aims**: '…to contribute to the availability of training in cultural sensitivities for Newham NHS staff…' (Roma Support Group, 2017: 4) **Key objectives**: 'a) Improved awareness and knowledge amongst Newham NHS staff in relation to Roma health status, health inequalities and cultural taboos and customs relevant in a health and safeguarding context which in turn would help staff gain confidence in providing more culturally appropriate patient care; b) Increased confidence of NHS staff in applying knowledge of Roma culture and health beliefs gained in practice; c) Increased ability of staff to suggest improvements to the service' (ibid: 4)	**Not stated**	**Training delivered**: 16 short sessions – Roma culture awareness 1 full day – working with Roma in a health context **Data collection methods**: Training registration form; training feedback form; training feedback follow-up form; observations and verbal feedback from trainers; follow-up telephone interviews **Problems with data collection were noted**	Reported feedback: **Increased awareness**; **increased confidence**; **increased ability to suggest improvements to services** Participants **requested targeted training about attitudes towards immunisation and reproductive health** in the Roma community	**Positive impact of training for healthcare staff** **Request for culturally specific targeted training**	Innovative training initiative, resulting in **overall positive feedback from participants** and recommendations for further, more focused, training Evaluation report produced for funders, so **may not be impartial** Prejudice against Roma and media-based bias are discussed but **strong focus on culture** **Less focus on structural factors**, e.g., Smith and Newton, 2016 not referenced in relation to immunisation uptake

	ROMA HEALTH UK – NO DIRECT QUOTES FROM ROMA OR PRACTITIONERS						
19	Training and Support 4 Services and Exiles (TS4SE) Co-operative Limited (2009), *Access and Health of Roma communities in the UK: Resource and Information Pack*, Manchester, TS4SE Co-operative Limited.	**Roma access and health – UK** **Resource and Information Pack/Training Module** **Training Objectives:** 'The objectives are: to familiarise UK healthcare staff with basic information about the Roma to familiarise UK healthcare staff with information about the political, social, economic and cultural backgrounds they have recently come from to link this information to the Roma's experience of accessing healthcare in the UK to establish good practice which can be disseminated for UK healthcare staff to provide services which are culturally sensitive and tailored to the specific needs of these diverse communities' (TS4SE Co-operative, 2009: 4).	**Resource and information pack; therefore, none stated**	**Not stated**	**Lack of attention to** Roma health in European public health circles **Lack of data** on Roma **health and living conditions** **Lack of trust and negative experiences of health systems** inhibit engagement, leading to **lack of awareness by policymakers** Gives information about health of the Roma in Central and Eastern Europe Focuses on lack of access to vaccination in countries of origin, hepatitis and TB, genetic diseases and disorders.	**Lack of data** **Lack of awareness of issues by policymakers**	**Positive inclusion of Roma** by this organisation, working with a wide range of migrant communities in the UK **Information** about Roma **stated as factual but, largely, without references** **No bibliography** given Slightly confusing, as gives health information relating to countries of origin, rather than the UK **Links health with living conditions** **Predates the NRIS, 2011** **No evaluation of training** available on TS4SE website (October 2018)
20	European Union Agency for Fundamental Rights (FRANET) National Focal Point (2012), *United Kingdom Social Thematic Study: The situation of Roma*, Human	Social Thematic Study - The Situation of **Roma - UK - includes health within wider brief** Prepared by Human Rights Law Centre,	**Not stated**	**Literature review/survey** of overall situation of Roma in UK, regarding **education, employment, healthcare, housing**	**Findings regarding healthcare**: **Invisibility** of GRT **in healthcare statistics** **Lack of culturally sensitised healthcare services**	**Lack of data** **Cultural barriers**	Roma voice - not directly - only via citation of other studies – **no quotations**

	Rights Law Centre, University of Nottingham.	University of Nottingham, for the Fundamental Rights Agency's multi-disciplinary research network **Purpose of Report not stated**		**and economic situation**	Context of **budget cuts impacting negatively** on support services for Roma **Lack of understanding** on part of healthcare professionals **regarding EU context** **Multiple barriers** (also faced by Gypsies and Travellers) Deteriorating health over age of 50 Life expectancy over 10% less than general population High infant mortality Low child immunisation levels **Mental health issues** Substance misuse issues Diabetes **Impact of poor housing and overcrowding on health of Roma**	**Negative impact of budget cuts** **Lack of understanding on part of healthcare professionals** **Multiple barriers** **Mental health issues** **Impact of poor housing and overcrowding on health**	Practitioner voice – No **Purpose of report not stated** Some **conflation of health issues for Roma and those for Gypsies and Travellers** **Locates Roma health issues in context of underfunded NHS** and **very briefly mentions the Decade of Roma Inclusion and the NRIS**
21	Roma Support Group (2016), *The Roma Community: An information leaflet for health care professionals and NHS personnel*, London, Roma Support Group.	**Information leaflet for health**, including NHS, **professionals** Information for all UK **based on work in Northeast London**, for use as a starting point in learning about the Roma community	**Not stated**	**Roma customs and taboos researched with Roma communities** based in London	**Cultural taboos**: Health, itself; female sexual or gynaecological health; age gap; **mental health the greatest health-related taboo subject** Notes some aspects of **social context of mental health issues**: Drug addiction; alcohol abuse; rape and domestic violence	**Cultural taboos, particularly mental health** **Social context of mental health issues** **Barriers to accessing services** **Language barriers**	**Accessible and practical introductory advice for healthcare professionals** **Focus on Roma culture and beliefs**, with acknowledgement that Roma community is diverse, with **limited focus on** discrimination and other **structural factors**

					Barriers to accessing services: Cultural taboos; **language barriers**, including cultural factors relating to interpreting; discrimination and distrust; lack of knowledge Offers **advice to enable relationships of trust and respect** between health professionals and Roma patients Notes **issues relating to language use by Roma people**: Vocabulary in second language may be limited; cultural rules and taboos result in limited health-related vocabulary; low levels of educational attainment result in difficulties regarding written communication	**Importance of building relationships of trust and respect**	Roma people not directly consulted - information extrapolated from the charity's work with Roma community members, so **may not be representative of wider Roma community** Researched in Northeast London, so **findings not necessarily generalisable**, although this is acknowledged
22	National Institute for Health and Care Excellence (NICE), (November 2018, September 2017, July 2016, September 2015), *Improving health and social care through evidence-based guidance*.	NHS evidence-based guidelines	Evidence-based – underlying theoretical position not stated	Comprehensive manual details methods of searching for, and selecting, evidence: 'Reviewing evidence is an explicit, systematic and transparent process that can be applied to both quantitative (experimental, observational and correlational) and qualitative evidence... The key aim of any review is to provide a summary of the relevant evidence to	In November 2018, 7 results for 'Roma': 3 referred to 'ROMA' – a term for a type of DNA testing, unrelated to Roma people; 2 referred to influenza, and flu vaccination: increasing uptake; 2 referred to community pharmacies:	Roma classified as 'underserved' : '… [due to] social circumstances, language, culture or lifestyle…' (NICE guidelines, November 2018). Underserved groups targeted regarding recognition of eligibility for	The reference to culture suggests ethnicity but Roma people, along with other Gypsies and Travellers are classed as 'underserved' (a euphemism for 'hard to reach'?), thus separating them from other recognised minority ethnic communities.

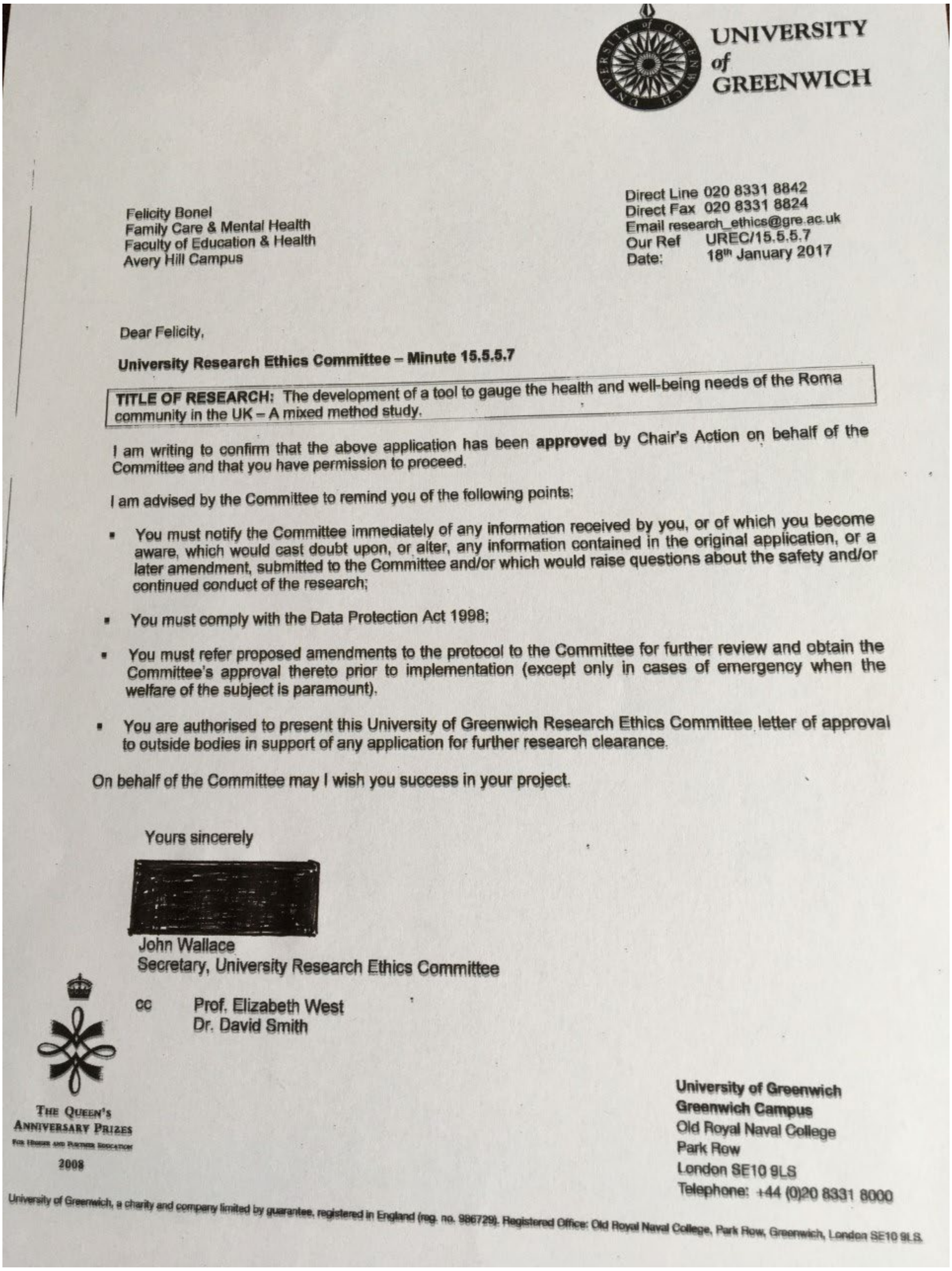
				ensure that the Committee can make fully informed decisions about its recommendations' (NICE guidelines manual, October 2014: 89).	promoting health and wellbeing	flu vaccination: People who are homeless or sleep rough; People who misuse substances; asylum seekers; Gypsy, Traveller and Roma people; people with learning disabilities; young people leaving long-term care	
23	Equality Commission for Northern Ireland (May 2014), *Racial Equality: Policy Priorities and Recommendations (Summary Version)*, Belfast, Equality Commission for Northern Ireland.	Sets out the Commission's policy priorities and recommendations to advance racial equality in Northern Ireland - includes Roma and health	**No primary research** **No theoretical position stated but does refer to multiple identities**	**Desk-based report**, citing mainly Northern Irish and some European reports	**Health**: Cites **research into migrant health and well-being** in Belfast (Belfast Health Development Unit, 2010) **Key barriers**: Lack of awareness; low levels of GP registration; fears about entitlements; frustration and stress in accessing healthcare; negative attitudes; **limited evidence suggests health outcomes are generally worse for Roma than for majority population** (Wright, 2011) **Lack of data** – prevents demonstration of policy effectiveness **Recommendations**:	**Roma health outcomes generally worse** than for majority population **Roma share experiences with other migrant groups** **Lack of data impacting on policy effectiveness** **Need for staff training**	Does not refer to the Decade of Roma Inclusion (2005 – 2015) or the NRIS (2011 – 2020) but **includes Roma in overall racial equality policy**, which may actually be more inclusive and effective **Incorporates Roma health issues into understandings about all migrant communities, whilst acknowledging that Roma difficulties may be greater** Cites Wright (2011) in relation to Roma but **Wright uses no references**

					Systematic collection, monitoring and evaluation of data; monitoring and evaluation across all relevant policy areas; endorsement of **revised Racial Equality Strategy and Action Plan**; anti-racist and cultural diversity **training for staff of public authorities**		
24	Wright, D. (2011), Roma Health and Wellbeing Issues in Northern Ireland, in *DHSSPS (2011): Equality Action Plan for the Department of Health Social Services and Public Safety*	Presentation delivered to Conference on minority ethnic health and wellbeing issues in Northern Ireland, 12th October 2011, Belfast	**No primary research**	**Sources not given**	**Mostly Romanian Roma, living in South Belfast** **General points**: **Cultural issues**; barriers to accessing healthcare; **language barriers**; healthcare workers unsure of **level of responsibility** '…in light of limited rights and entitlements' (Wright, 2011) **Roma children**: Vaccination issues; lack of data; high mobility makes follow-up difficult; overcrowding; poverty and hygiene issues; issues regarding feeding of babies; lack of dental care; child protection issues **Roma adults**: Poverty, poor diet and living conditions; lung and heart disease, diabetes; dental caries; stress and poverty contributing	**Need for staff training**	**No references given, so context and reliability of content could not be determined by the conference audience** **Issues presented may not be generalisable to all Roma groups in all parts of the UK** **Unclear as to what is meant by '…in light of limited rights and entitlements' (Wright, 2011). By 2011, all A8 and A2 nationals had full EU rights under the Freedom of Movement and Residence Directive (2004).** **Some reference to structural factors but tends towards a cultural understanding of, and solution to, Roma health and well-being issues**

					to mental health issues; large families; no health screening; lack of GP access, leading to inappropriate use of A&E **Recommendations**: Culturally competent health visiting and family support; Roma health mediators		
25	Shallice, A. and Greason, L. (27th January 2017), *Women & Equalities Select Committee inquiry: Written evidence submitted by Roma Support Group (RSG)*, London, Roma Support Group.	Submission to Women and Equalities Select Committee: 'Tackling inequalities faced by Gypsy, Roma and Traveller communities' – UK/ GRT - includes Roma health	**No primary research**	**Method**: **'…based upon the experience of RSG, an NGO responding to the needs of distinct Roma communities in London and providing a strategic overview of the needs of Roma communities throughout the UK, in collaboration with others' (Shallice and Greason, 2017: 1).**	**Roma not included in 2011 Census** **New Roma Read Codes for GP systems nationally from April 2016** – therefore, within NHS primary care Roma can be recorded by national origins and linguistic competence Self-ascription dependent on trust **Roma distinct from Gypsies and Travellers** but common cultural ground exists Health findings: Issues faced in accessing **culturally competent healthcare**; distinct **lack of research**; issues of **transiency**; **communication difficulties**; **difficulty registering with GPs**; **lack of information** regarding UK healthcare system	**Lack of data** **New Roma Read Codes for GP systems** **Roma distinct from Gypsies and Travellers** **Lack of research** **Communication difficulties** **Need for culturally competent healthcare provision**	**Health section necessarily limited** by inclusion within short submission **Generalised information based on work with RSG clients**

					Recommends use in Sheffield of **Roma health advocates and health trainers**		
26	National Roma Network (January 2017), *A response to Women and Equalities Committee's inquiry on tackling inequalities faced by Gypsy, Roma and Traveller communities in the UK,* Yorkshire, National Roma Network.	Submission to Women and Equalities Select Committee: 'Tackling inequalities faced by Gypsy, Roma and Traveller communities' – UK/ Roma – includes brief mention of some Roma health issues Compiled by Migration Yorkshire on behalf of the NRN – '…a partnership of voluntary and community organisations, Roma community groups and individuals, representatives from local and central government and statutory organisations, universities and researchers' (NRN, 2017: 2).	**No primary research**	Methods not stated but **information obtained from government documents and other literature**	Key issues: **Language difficulties** in health context; **Roma rarely highlighted in national strategies** aiming to tackle exclusion of GRT communities; Department of Health recommendations do not specifically include Roma; National **Health Inclusion Board cites good practice relating to Roma health needs**; **Roma excluded from 2011 Census**; without reliable data, issues seen as 'local' and 'anecdotal' (NRN, 2017: 6); **low life expectancy**; **lack of knowledge of services**; **no formal communication mechanisms** between national and local policy-makers and Roma; **difficulties accessing health services**; **issues identified by earlier reports still prevalent or worsening**; leads to **negative effect on Roma mental health**; removal from UK for not exercising EU treaty rights; **concern regarding impact of Brexit** on Roma; **Roma not a homogenous group**; specific **difficulties facing Roma women**, e.g. accessing maternity services, domestic violence or social services involvement	**Language barriers** **Lack of national strategy** **Lack of data** **Lack of progress** **Mental health issues** **Impact of Brexit** **Roma not homogenous** **Difficulties facing Roma women, including health issues**	Partnership including local and central government responding to central government inquiry Not based on a systematic literature review **Low life expectancy noted but not referenced** However, **a strong submission, pointing to many significant issues** faced by migrant Roma people in the UK, including difficulties in the areas of health and well-being

27	Fremlová, L. and Anstead, A. (2010/2011), *Discrimination as standard*, Runnymede Bulletin, Winter 2010-2011, issue 364.	Runnymede Bulletin on situation of Roma living in the UK f	**No primary research**	Information drawn from study by Fremlová and Ureche, 2009	**Severe overcrowding** often **leads to poor health** **Lack of data**, leading to lack of knowledge, leading to limited ability of local authorities and other organisations to provide suitable services for Roma Some local authorities employ **Roma outreach staff to engage Roma regarding family health**, but funding for these posts threatened in 2011	**Social determinants of health** **Lack of data leading to poor provision** **Roma health outreach staff**	Repetition of studies by Fremlová, 2009; and by Fremlová and Ureche, 2009 – no new information Effectiveness of Roma health outreach staff assumed but not evidenced



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Felicity Bonel
Family Care & Mental Health
Faculty of Education & Health
Avery Hill Campus

Direct Line 020 8331 8842
Direct Fax 020 8331 8824
Email research_ethics@gre.ac.uk
Our Ref UREC/15.5.5.7
Date: 18th January 2017

Dear Felicity,

University Research Ethics Committee – Minute 15.5.5.7

TITLE OF RESEARCH: The development of a tool to gauge the health and well-being needs of the Roma community in the UK – A mixed method study.

I am writing to confirm that the above application has been **approved** by Chair's Action on behalf of the Committee and that you have permission to proceed.

I am advised by the Committee to remind you of the following points:

- You must notify the Committee immediately of any information received by you, or of which you become aware, which would cast doubt upon, or alter, any information contained in the original application, or a later amendment, submitted to the Committee and/or which would raise questions about the safety and/or continued conduct of the research;
- You must comply with the Data Protection Act 1998;
- You must refer proposed amendments to the protocol to the Committee for further review and obtain the Committee's approval thereto prior to implementation (except only in cases of emergency when the welfare of the subject is paramount).
- You are authorised to present this University of Greenwich Research Ethics Committee letter of approval to outside bodies in support of any application for further research clearance.

On behalf of the Committee may I wish you success in your project.

Yours sincerely

[redacted]

John Wallace
Secretary, University Research Ethics Committee

cc Prof. Elizabeth West
Dr. David Smith

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HEALTH AND WELL-BEING IN THE ROMA COMMUNITIES

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Revised Interview Schedule

Title of research: The development of a tool to gauge the health and well-being needs of the Roma community in the UK – A mixed method study

Researcher's introduction: The researcher (Felicity Bonel) introduces herself, making a brief reference to her previous work with Roma families, and describing her role. The researcher also introduces the interpreter. The researcher tells the participant that there are no 'correct' or 'incorrect' answers and that the research is interested in their own views and experience. The participant is told that they do not have to speak about anything they are not comfortable with and is reminded about the arrangements for confidentiality and anonymity.

Explanation of the research: The researcher briefly covers the key points in the information sheet for participants and restates the aims of the research.

Aims of the research:

1) to explore your experiences of health care and well-being services in the UK;
2) to explore your personal or family health and well-being needs;
3) to explore your experiences of health care in other countries;
4) to explore how Roma health care in previous generations may affect your experiences now;
5) to examine any barriers to accessing health care services that you may have experienced in the UK;
6) to develop a survey questionnaire to be used by Health Authorities and non-governmental organisations across the UK, to improve their communication about health and well-being with Roma residents. The questionnaire will be developed in consultation with Roma community members, as well as with staff of the Health Authorities and non-governmental organisations.

Introduction to the interview: The researcher thanks the participant for taking part in the research and asks them to introduce themselves, stating their nationality, London borough of residence and how long they have lived in the UK. The researcher asks the participants to state their gender and age group, and the languages that they speak. The researcher asks the participant to describe the composition of their family, such as the number of their children and grandchildren.

The researcher asks the participant if they have any concerns, and address these before commencing the interview.

The interview:

Topic One – General use of health care and well-being services:

'Do you have experiences of health care or well-being services in the UK that you would particularly like to talk about?' General experiences

'Can you tell me something about your experiences of health and well-being services in your own, or other, countries?' Comparison between countries

‘Have you, or anyone you know, experienced any difficulties or barriers when using health care and well-being services in the UK?’ Barriers to access

‘Do you think your use of these services has been affected in any way by your immigration status?’ Impact of migration

‘Do you think that, in Roma culture, health and well-being are seen in any ways differently from the ways they are seen by non-Roma people?’ Comparison between Roma culture and UK mainstream culture

Topic Two – Specific aspects of health care and well-being services:

‘Is there anything you would like to say about the health and development of babies and children, pregnancy or childbirth?’ Maternity services, infants and children

‘Would you like to say anything about the care and well-being of elderly people in your community?’ Care of the elderly

‘Thinking back to your grandparents, for example, can you tell me how people in Roma communities looked after their health before modern medical treatments became available?’ Roma health care in previous generations

‘I’d like to ask you now about mental health, stress and taking care of emotional needs and feelings. Is there anything you would like to say about these health issues?’ Mental health and well-being

‘Some doctors think that smoking among adults and hearing problems among children are important issues for Roma people. Do you think they are right?’ Smoking and childhood hearing impairment

‘Can you suggest any ways in which health and well-being services could be improved for Roma people? Is there anything Roma people could do, to make their experiences of these services better for themselves?’ Improvements to services and experiences

Topic Three – Other aspects of health and well-being care / Clarifications:

‘Is there anything else you would like to say, in relation to the health and well-being of people within your community?’

‘Is there anything we’ve discussed that you would like to make clearer, or that you would like me to clarify?’

Thanks:

The researcher thanks the participant for taking part in the interview and reminds the participant that, should they wish to take part in the consultation regarding the survey tool, they should let the researcher know. The researcher reminds the participant that the researcher’s contact information can be found on the consent form. The researcher thanks the interpreter for making the discussion possible.

Faculty of Education and Health
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Avery Hill Road
London SE9 2UG

F.M.Bonel@greenwich.ac.uk

Date

Address to manager of TES Coordinator

Dear name of manager of TES Coordinator

Re: The development of a tool to gauge the health and well-being needs of the Roma community in the UK – A mixed method study

Having spent many years coordinating the Gypsy, Roma and Traveller Education Services in Lambeth and Greenwich, I am now a funded research student at the University of Greenwich.

My research study is looking at the health and well-being needs of people in the Roma communities, initially in London. The findings of the fieldwork in London will be used to inform the development of a survey tool and good practice guidelines for use by Health Authorities and community organisations across the UK, to support improved access to appropriate services. I propose to carry out individual interviews and focus groups in a range of authorities across Greater London, in order to develop a profile of the health and well-being of the Roma communities. The planned timescale for the fieldwork is between 1st September 2016 and 28th February 2017.

Following a presentation of the study to a meeting of the London Traveller Education Coordinators' Group in April of this year, and the interest shown by name of LA TES

Coordinator, I would like to ask if you would be agreeable to my conducting interviews with Roma adults known to name of LA Traveller Education Service.

I want to give people as little additional work as possible and will do as much as I can myself of the work to make arrangements. I shall be making the required application to the University Ethics Committee before starting any fieldwork and would be happy to answer any queries that you may have. I enclose a copy of the Information for Organisations and Information for Participants sheets.

Further information may be obtained from the study supervisor, Dr David Smith, Principal Lecturer in Sociology, Faculty of Education and Health, University of Greenwich. D.M.Smith@greenwich.ac.uk 020 8331 9427

Yours sincerely,

Felicity Bonel
MPhil/PhD Student
Faculty of Education and Health
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Cc: name of Traveller Education Service Coordinator

HEALTH AND WELL-BEING IN THE ROMA COMMUNITIES

Information for organisations

The University of Greenwich is undertaking the following research study:

The development of a tool to gauge the health and well-being needs of the Roma community in the UK – A mixed method study

Information currently available on the health and well-being of Roma communities suggests a wide range of areas of difficulty, including significant barriers to accessing appropriate services within the UK. Roma people from the range of communities living in four London boroughs are invited to participate in individual interviews and/or focus groups, where health and well-being issues will be discussed. Information gathered will be analysed, together with information from existing reports, to give an overall picture of key areas of need and difficulties experienced in terms of accessing culturally appropriate health and well-being services.

On the basis of the information collected a survey tool will be devised, to be used by Health Authorities and non-governmental organisations across the UK. This will be shared with a range of partners, including Roma participants, and will be adjusted according to feedback. The anticipated final outcome would be UK-wide use of the survey tool to gather data, in order to inform best practice for health and well-being services for all Roma communities within the UK.

Participation is entirely voluntary, and participants will be asked to sign a form giving their consent to taking part in the study. Participants will be free to withdraw, should they wish to do so, up to the point at which their data have been amalgamated into the study. All information gathered will be made anonymous. Audio tapes will be stored securely in locked cabinets at the University, and electronic data will be password protected or encrypted. The University of Greenwich stores research information securely for five years. The outcomes of the study will be presented in written form as a post-graduate research thesis.

Where necessary, the participant information leaflet and consent form will be translated into an appropriate language and interpreters will read this information to potential participants. Interpreters will also be available to help facilitate the interviews and the focus groups. The languages to be used will be discussed with the Roma participants beforehand. Participants will be asked to talk about, or to discuss, open-ended questions relating to health and well-being issues. Interviews and focus groups will be audio recorded, to ensure accuracy.

The researcher, Felicity Bonel (F.M.Bonel@greenwich.ac.uk), has many years' experience of working with Roma children and families in London, within schools and the education system. She has a good understanding of the difficulties that may be faced by Roma families in the UK, and of cultural factors that should be taken into account. The researcher will be supervised by Dr Carlos Moreno-Leguizamon, Senior Lecturer in Health Development at the University of Greenwich (C. J. Moreno@greenwich.ac.uk /020 8331 9306).

HEALTH AND WELL-BEING IN THE ROMA COMMUNITIES

Information for participants

Title of study:

The development of a tool to gauge the health and well-being needs of the Roma community in the UK – A mixed method study

Invitation:

You are invited to take part in this research project. You should only participate if you wish to do so and you will be free to withdraw from the project at any time, until your data have been amalgamated into the study. If you decide not to participate, this will not disadvantage you in any way. Before deciding whether you wish to take part, it is important for you to understand what this will involve, and why this research is being carried out. The following information will explain the purpose of the research. Please ask if you would like more information or if there is something you do not understand.

Why we are doing this study:

Information currently available on the health and well-being of Roma communities suggests a wide range of areas of difficulty, including significant barriers to accessing appropriate services within the UK. This study will explore these issues further through conversations with Roma people living in four London boroughs. The aims of the study are to:

7) Explore your experiences of health care and well-being services in the UK;
8) Explore your personal or family health and well-being needs;
9) Explore your experiences of health care in other countries;
10) Explore how Roma health care in previous generations may affect your experiences now;
11) Examine any barriers to accessing health care services that you may have experienced in the UK;
12) Develop a survey questionnaire to be used by Health Authorities and non-governmental organisations across the UK, to improve their communication about health and well-being with Roma residents. The questionnaire will be developed in consultation with Roma community members.

It is hoped that the use of the survey questionnaire, and better communication, will enable health and well-being services across the UK to be improved for the benefit of Roma community members.

All the information you give will be treated confidentially and will be anonymised.

Study details:

If you decide to take part in this study, you will be invited to participate in an individual interview or in a focus group with other Roma people, where health and well-being issues will be discussed. Individual interviews will last for approximately one hour and focus groups will last for between one and one and a half hours. Interviews will be with the researcher, and the researcher will also guide the focus groups.

If you need one, an interpreter will be available to ensure that you fully understand the details of the study and the questions asked. The interpreter will use a language you feel comfortable speaking. You can also ask somebody else to attend with you if you wish.

Your responses to the questions asked in the interview or the focus group will be recorded by the researcher. This will also be completely anonymous. Everyone who takes part will be given a number that will correspond with their responses, so nobody will be able to identify you apart from the researchers and other people in the group.

Nothing that you tell the researcher in the interview or the focus group will be passed on to anyone else in a way that could identify you. However, if a child is reported to be in danger, or in the case of child protection issues, the researcher will have a duty to pass on this information to the relevant authorities. In this case, the duty of the researcher to keep the participant's identity anonymous will no longer be guaranteed.

All the recorded information will be written up and all names will be removed. The organisation that has arranged your interview will not be named and you, other members of the focus groups, and staff of your organisation will be asked to keep all aspects of the study confidential.

Taking part in the research:

Participation in this study is entirely voluntary.

If you decide to take part, you will be given a copy of this information sheet to keep.

You will be asked to sign a form giving your consent to taking part. The information sheet and consent form will be translated, and can be read to you, if necessary.

As participation is anonymous, it will not be possible for you to withdraw once your data have been amalgamated into the study.

We hope that the results of this research, and the contribution of Roma community members, will be used to improve access to appropriate health care and well-being services for members of the Roma communities across the UK.

You will be able to obtain a copy of any published results from the researcher if you would like to see them.

Contacts for further information:

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ZDROWIE I DOBRE SAMOPOCZUCZICE W SPOLECZNOŚCI ROMSKIEJ

UNIVERSITY of GREENWICH

Informacje dla uczestników

Tytuł badania:

Rozwinięcie narzędzi w celu pomiaru potrzeb związanych ze zdrowiem i samopoczuciem wsród spoleczności Romskiej w Wielkiej Brytanii – metody mieszane.

Zaproszenie:

Zostali Państwo zaproszoni by wziąc udział w projekcie naukowym. Uczesnictwo w tych badaniach jest dobrowolne. Możecie Państwo zrezygnować z uczesnictwa do momentu, w którym informacje przekazane przez was nie sa udostępnione do użytku publicznego. Jeśli nie zdecydują się Państwo na branie udziału w tych badaniach w żaden sposób nie wpłynie to na was. Przed zdecydowaniem się na wzięcie udziału w projekcie ważne jest by Państwo zrozumieli, jaki jest jego cel. Jeśli potrzebujesz wiecej informacji lub czegos nie rozumiesz nie wahaj sie zapytac.

Dlaczego podejmujemy te badania:

1. Zbadanie twoich doświadczeń związanych z służba zdrowia w Wielkiej Brytanii.
2. Zrozumienie twoich i twojej rodziny potrzeb zdrowotnych.
3. Zbadanie twoich doświadczeń związanych ze służba zdrowia w innych krajach.
4. Zbadanie jak opieka zdrowotna Romów w poprzednich pokoleniach wpływa na Ciebie dzis.
5. Zrozumienie barier, które napotykasz w uzyskiwaniu pomocy z ramienia służb zdrowia w Wielkiej Brytanii.
6. Stworzenie ankiety, która bylaby uzywana przez sluzby zdrowia oraz organizacje pozarządowe w Wielkiej Brytanii, która pomoże w komunikacji z Romami. Ankieta będzie stworzona przy pomocy członków Romskiej społeczności.

Mamy nadzieje, że dzięki użyciu takiej ankiety i lepszej komunikacji między służbami zdrowia a Romami możliwe będzie polepszenie dostępnosci usług dla tych drugich.

Wszystkie informacje, które Państwo udzielą będą poufne i anonimowe

Szczegóły badań:

Jesli zdecydujesz sie na wzięcie udziału w tych badaniach, zostaniesz zaproszony na indywidualna rozmowa badz na uczesnictwo w panelu, w którym będą Romowie. Podczas tej rozmowy tematy zdrowotne i związane z dobrym sampoczuciem będą poruszane. Indywidualne rozmowy/wywiady będę trwały około godziny. Rozmowy w grupie między jedna godziną a połtora. Wywiad zostanie przeprowadzony przez badacza. Rozmowy w grupie będą ukierunkowywane rowneż przez badacza.

Jeśli zajdzie taka potrzeba – tłumacz będzie obecny podczas rozmow aby uczestnik/ uczestnicy mieli możliwość pełnego zrozumienia pytań.

Odpowiedzi na pytania będą nagrywane bądź zanotowane przez badacza. Wszystko będzie odbywało się anonimowo. Każda osoba, która weżmie udział w wywiadzie bądz w panelu będzie miała nadany swój numer identyfikacyjny. Nikt oprócz osoby przeprowadzającej badania oraz osób, które będą brały udziłł w panelu nie będzie mógl wstanie Państwa zidentifikować.

Nic co zostanie powiedziane podczas wywiadu przeprowadzonego z Państwem bądz podczas panelu nie zostanie przekazane w sposób, ktory umożliwi Państwa zidentifikowanie. Jesli osoba poniżej 18ego roku życia podczas przeprowadzania wywiadu lub panelu wyjawi, że jest w jakimkolwiek niebezpieczeństwie, badacz ma obowiązek zgłoszenia tego do odpowiednich służb.

Wszystkie nagrane informacje zostaną przepisane a imiona wymazane. Organizacja, która zorganizowała Państwa wywiad nie zostanie wspomiana. Państwo zarowno jak i inni uczestnicy zostaną poproszeni o nie wyjawianie żadnych informacji osobom postronnym.

Branie udziału w badaniach:

Uczesnictwo jest całokowicie dobrowolne.

Jesli zdecydują się Państwo na wzięcie udziału w tym badaniu, otrzymają Państwo kopie tego dokumentu.

Zostana Panstwo poproszeni o podpisanie formularza wyrazającego zgodę na Państwa uczestnictwo w badaniach.

W związku z tym że badania sa anonimowe, nie będzie możliwosci wycofania swoich wypowiedzi (ich zidentyfikowania), gdy zostaną one włączone w raport.

Mamy nadzieję, że wyniki tych badań wpłyną na polepszenie świadczenia jakości ze strony służb zdrowia dla Romów w Wielkiej Brytani.

Będą mieli Państwo możiwość otrzymania własnej kopii raportu.

Wiecej informacji:

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SĂNĂTATEA ŞI BUNĂSTAREA ÎN COMUNITĂŢILE DE ROMI

INFORMAŢII PENTRU PARTICIPANŢI

Titlu

Dezvoltarea unui instrument de măsurare a nevoilor privind sănătatea şi bunăstarea comunităţilor de Romi în UK – Studiu prin metode mixe

Invitaţie:

Sunteţi invitaţi să luaţi parte în acest proiect de cercetare. Participarea dumneavoastră în această cercetare este voluntară şi puteţi să vă retrageţi din proiect în orice moment, înainte ca informaţiile furnizate de dumneavoastră să fie procesate în cadrul cercetării. Nu o să fiţi dezavantajat în nici un fel dacă nu doriţi să fiţi implicaţi în studiu. Înainte de a vă decide este important să înţelegeţi ce implică acest lucru şi care este motivul acestei cercetări. Informaţiile următoare vă vor explica scopul acestei cercetări. Vă rugăm să întrebaţi dacă aveţi nevoie de mai multe informaţii sau dacă nu înţelegeţi ceva.

De ce facem acest studiu?

Informaţiile disponibile momentan privind sănătatea şi bunăstarea comunităţilor de Romi indică o arie diversă de dificultăţi, incluzând bariere semnificante în accesarea de servicii necesare, în UK. Acest studio va explora aceste dificultăţi detaliat, prin conversaţii cu persoane de etnie Romă, rezidente în 4 sectoare din Londra. Scopurile acestui studiu sunt:

13) Explorarea experienţelor dumneavoastră în accesarea serviciilor de sănătate şi bunăstare în UK;
14) Explorarea nevoilor personale sau ale familiei dumneavoastră privind sănătatea sau bunăstarea;
15) Explorarea experienţelor dumneavoastră privind serviciile de sănătate din alte ţări;
16) Explorarea privind experienţele avute de generaţiile trecute de Romi in accesarea serviciilor de sănătate şi cum acestea vă afectează în prezent;
17) Examinarea barierelor avute în accesarea de servicii de sănătate în UK;
18) Dezvoltarea unui chestionar care va fi folosit de către autotităţile din domeniul sănătăţii şi de către organizaţiile non-guvernamentale din UK pentru a îmbunătăţii comunicarea privind sănătatea şi bunăstarea cu rezidenţii de etnie Romă. Chestionarul va fi dezvoltat în consultare cu membrii ai comunităţii de romi.

Se intenţionează ca, prin utilizarea chestionarului, şi printr-o comunicare mai bună, să se imbunătăţească accesul la servicii de sănătate şi bunăstareîn UK, pentru comunităţile de Romi.

Informaţiile furnizate de dumneavoastră vor fi tratate în mod confidenţial şi vor fi făcute anonime.

Detaliile studiului:

Dacă vă decideţi să luaţi parte în acest studiu veţi fi invitat/ă să luaţi parte într-un interviu individual sau într-un focus grup cu alte persoane de etnie Romă unde se vor discuta probleme privind sănătatea şi bunăstarea. Interviurile individuale vor dura aproximativ o oră, iar întâlnirile focus grup vor dura între o oră şi o oră şi treizeci de minute. Interviurile for fi susţinute de către cercetător şi acesta va susţine de asemenea şi intâlnirile de tip focus grup.

Dacă aveţi nevoie, un traducător va fi disponibil pentru a se asigura faptul că întelegeţi pe deplin detaliile studiului şi întrebările puse. Pentru confortul dumneavoastră traducătorul va folosi un limbaj familiar dumneavoastră. Dacă doriţi, puteţi să fiţi însoţiţi de către cineva.

Răspunsurile date de dumneavoastră în timpul interviului vor fi înregistrate de către cercetator. Acestea vor fi făcute anonime. Toţi participanţii la studio vor primi un număr care va corespunde cu răspunsurile acestora şi prin acest mod singurele persoane care vor putea să vă identifice vor fi cercetătorii şi alte persoane din acest grup.

Nimic din ceea ce spuneţi cercetătorului în timpul interviului sau focus grup-ului nu va fi transmis altcuiva astfel încât să puteţi fi identificat. Totuşi, dacă un minor este pus în pericol, sau într-un caz privind protecţia copilului, cercetătorul are obligaţia de a transmite informaţii către autoritatea competentă. În acest caz, obligaţia cercetătorului de a păstra identitatea participantului anonimă nu va mai putea fi garantată.

Toate informaţiile înregistrate vor fi, ulterior, scrise şi toate numele menţionate vor fi şterse. Asociaţia care a organizat intervievarea dumneavoastră nu va fi menţionată şi dumneavoastră, alţi participanţi la focus grup şi personalul asociaţiei sunteţi rugaţi să pastraţi toate detaliile privind acest studiu confidenţiale.

Participarea în cadrul acestui studiu:

Participarea în cadrul acestui studio este pe deplin voluntară.

Dacă veţi decide să participaţi, veţi primi o copie a acestei notă de informare.

Vi se va cere să semnaţi un formular prin care dumneavoastră veţi da consimţământul să participaţi în cadrul studiului. Nota de informare şi consimţământul vor fi traduse, şi, dacă este necesar, vor putea fi citite pentru dumneavoastră de către o altă persoană.

Având învedere ca participarea este anonimă, dupa introducerea datelor în studiu, nu va fi posibilă retragerea din studiu.

Sperăm ca rezultatele acestei cercetări, şi contribuţia membrilor comunităţii de Romi, vor fi utilizate pentru a îmbunătăţii accesul la servicii decente de sănătate şi bunăstare pentru membrii comunităţilor de Romi din UK.

Veţi avea posibilitatea de a obţine o copie a oricărui rezultat publicat în urma cercetării daca veţi dori acest lucru.

Pentru mai multe informaţii puteţi contacta:

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SAU:

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HEALTH AND WELL-BEING IN THE ROMA COMMUNITIES

UNIVERSITY of GREENWICH The University of Greenwich is undertaking the following research study:

The development of a tool to gauge the health and well-being needs of the Roma community in the UK – A mixed method study

PARTICIPANT CONSENT FORM

To be completed by the participant. If the participant is under 18, to be completed by the parent / guardian / person acting *in loco parentis*.

If the participant for any reason cannot complete this form themselves, to be completed on their behalf by . Date

- I require an interpreter in order to take part in the study Yes / No.
- I have read the information sheet about this study in English / in my home language.
- I have had the information sheet about this study read to me in English / in my home language.
- I have had an opportunity to ask questions and discuss this study.
- I have received satisfactory answers to all my questions.
- I have received enough information about this study.
- I understand that I am:
  - free to withdraw from this study at any time (until such date as this will no longer be possible, which I have been told);
  - free to withdraw from this study without giving a reason for withdrawing.
- I understand that if I am, or intend to become, a student at the University of Greenwich, withdrawal from the study will not affect my future with the University.
- I understand that my research data may be used for a further project in anonymous form, but I am able to opt out of this if I so wish, by ticking here. ☐
- I have been given a participant identification number, to enable withdrawal of my information.
- I agree to take part in this study.

Participant identification number	
Signed (participant)	Date
Name in block letters	
Signed (parent / guardian / other) (if under 18)	Date
Name in block letters	
Signature of researcher	Date

This project is supervised by: Dr Carlos Moreno-Leguizamon, University of Greenwich
Researcher’s contact details (including telephone number and e-mail address): Felicity Bonel, F.M.Bonel@greenwich.ac.uk , 020 8331 9306 (Dr C. Moreno-Leguizamon)

UNIVERSITY
of
GREENWICH

ZDROWIE I DOBRE SAMOPOCZUCZICE W SPOLECZNOŚCI ROMSKIEJ

Rozwinęcie narzędzi w celu pomiaru potrzeb związanych ze zdrowiem i samopoczuciem wśród społecznosci Romskiej w Wielkiej Brytanii – metody mieszane.

ZGODA UCZESTNIKA

Jeśli uczestnik nie może sam wypelnić formularza z jakichkolwiek względów, może on zostać wypełniony przez kogoś innego. . Data

- Potrzebuję tłumacza by móc uczestniczyć w tym projekcie.
- Przeczytałem/am informacje na temat tego projektu po angielsku/ po polsku
- Ktoś przeczytał mi informacje na temat tego projektu po angielsku/ po polsku
- Miałem/łam możliwość zapytać o dodatkowe informacje dotyczace projektu.
- Otrzymałem/łam satysfakcjonujące odpowiedzi na moje pytania.
- Otrzymałem/łam odpowiednią ilośc informacji odnośnie badań.
- Rozumiem, że mam możliwość:
- Wycofania się z tych badań w każdym momencie.
- Wycofania się z tych badań bez podawania przyczyny.
- Rozumiem, ze jeśli jestem studentem lub zamierzam studiowac na University of Greenwich, moje wycofanie się z badań w żaden sposób nie wpłynie na moje studiowanie.
- Rozumiem, że moje wypowiedzi mogą zostać użyte anonimowo w innych badaniach. Jeśli nie zgadzasz śię na to, proszę zaznaczyć tutaj
- Otrzymałem/łam swój numer identyfikacyjny, który umożliwi mi wycofanie swoich informacji jeśli zajdzie taka potrzeba.
- Wyrażam zgodę na uczestniczenie w tych badaniach.

Numer identyfikacyjny uczestnika:	
Podpis uczestnika:	Data
Imię i nazwisko / drukowane litery:	
Podpis (rodzica / opiekuna / inne) (jesli uczestnik jest poniżej 18 roku życia)	Data
Imię i nazwisko / drukowane litery	
Podpis badacza	Data
Projekt jest nadzorowany przez: Dr Carlos Moreno-Leguizamon, University of Greenwich	
Dane badacza: (numer telefonu oraz email): Felicity Bonel, F.M.Bonel@greenwich.ac.uk , 020 8331 9306 (Dr C. Moreno-Leguizamon)	

SĂNĂTATEA ŞI BUNĂSTAREA ÎN COMUNITĂŢILE DE ROMI

Universitatea Greenwich implementează în prezent umătorul studiu:

Dezvoltarea unui instrument de măsurare a nevoilor privind sănătatea şi bunăstarea comunităţilor de Romi în UK – Studiu prin metode mixte

CONSIMŢĂMÂNT

A fi completat de către participant. Dacă participantul este sub 18 ani, să se completeze de către părinte/tutore sau persoană responsabilă.
Dacă, din orice motiv, participantul nu poate completa consimţământul, formularul poate fi completat în numele acestora de către: Data:

- Am nevoie de un traducător pentru a putea participa la studiu DA/NU.
- Am citit nota de informare privind acest studiu în ENGLEZĂ/ ÎN LIMBA MATERNĂ
- Am avut oportunitatea de a pune întrebări şi discuta privind acest studiu.
- Sunt mulţumit de răspunsurile primite la întrebările mele.
- Sunt mulţumit de informaţiile primite referitoare la acest studiu.
- Înţeleg că:
    - Pot să mă retrag din cadrul cercetării în orice moment (până în momentul când acest lucru nu va mai fi posibli, după cum am fost informat anterior)
    - Pot să mă retrag, nemotivat, din cadrul acestui studiu.
- Înţeleg faptul că, dacă sunt, sau intenţionez sa devin student al Universităţii Greenwich, retragerea mea din cadrul cercetării nu imi va afecta viitorul în cadrul Universităţii.
- Sunt conştient de faptul că datele furnizate de mine pot fi utilizate într-un proiect viitor, în mod anonim dar pot să nu fiu de acord cu acest fapt bifând căsuţa alăturată
- ☐
- Am primit un număr de identificare a participantului pentru a avea posibilitatea de a retrage informaţiile furnizate de mine în cadrul studiului
- Sunt de accord să particip în cadrul acestui studiu

Număr de identificare a participantului	
Semnătură (participant)	Data
Nume (Cu litere mari)	
Semnătură (părinte / tutore / altul) (dacă participantul este minor)	Data
Nume (Cu litere mari) Name in block letters	
Semnătura cercetătorului Signature of researcher	Data Date
Proiect coordonat de: Dr. Carlos Moreno-Leguizamon, Universitatea Greenwich	

Contact cercetător (incluzând numărul de telefon şi adresa de e-mail):
Felicity Bonel, F.M.Bonel@greenwich.ac.uk, 020 8331 9306 (Dr. C. Moreno-Leguizamon)

Transcriber’s Confidentiality Agreement

The development of a tool to gauge the health and well-being needs of the Roma community in the UK – a mixed method study

I undertake to preserve the anonymity of all participants in the above-named study, and not to divulge any information shared by participants taking part in individual interviews or focus groups.

Signed: Sarah Bartlett

Dated: 18 05 2017

Felicity Bonel, Department of Family Care and Mental Health, Faculty of Education and Health,
University of Greenwich, Southwood Site, Avery Hill Campus, London SE9 2UG
F.M.Bonel@greenwich.ac.uk

Trustworthiness criteria

Domain	**Explanation**
Credibility (Does the study represent a true picture of the phenomenon being examined?)	The limitations of the present study's participant group, and its setting, have been clearly stated. As a result, the study represents a clear picture of the experiences of its particular participant group, in its particular setting, and at a certain time.
Transferability (Is sufficient detail provided, of the context of the fieldwork, so that the findings might be justifiably applied to another setting?)	The context of the study was described in detail, including the area of London in which it took place, and the settings in which the interviews were carried out. The steps followed by the researcher to contact organisations, and to arrange interviews and interpreters, could be applied in another setting.
Dependability (Could the study be repeated by a different researcher?)	It is acknowledged that the present researcher's previous contacts were beneficial in enabling access to participants, but such contacts would not be essential for the study to be repeated by a different researcher.
Confirmability (Do the findings emerge from the data, rather than from the researcher's predispositions?)	This is a post-structuralist study, whereby the involvement of the researcher, and the influence of the researcher's beliefs, biases, previous experience and so forth, are understood inevitably to influence the findings. However, and at the same time, careful steps were taken to demonstrate that the analysis of the data from the interviews was based strongly on the transcribed

	conversations. A focus on the voices of the participants allowed for considerable space to be given to direct quotations. The influence of processes of interpreting and translation was also recognised.

Working with Roma clients: Guidelines for healthcare professionals

Introduction:

- Roma people living in London and the wider UK belong to communities that have migrated from Central and Eastern European countries, either as asylum seekers prior to their countries gaining membership of the EU, or under the terms of the EU Free Movement Directive (Official Journal of the European Union, 2004/58/EC). Many younger Roma individuals, including children, have been born in the UK, and many Roma have British nationality or UK settled status.

- Roma people belong to the worldwide Romani diaspora, believed to have its origins in northern India. It is thought that Romanies left India around a thousand years ago, although the exact dates and reasons for leaving are uncertain. In the UK, Roma people are often included within the Gypsy, Roma and Traveller grouping. Here, 'Gypsy' refers to Romani people who arrived in Britain in the sixteenth century – Romanichals in England and Scotland, and Kale in Wales (Fraser, 1995). The term 'Traveller' is used to describe members of communities of Scottish and Irish origin, minority ethnic groups identified very closely with a nomadic lifestyle.

- The first language of the majority of Roma people is Romanes, the Romani language, which has its roots in Sanskrit (Hancock, 2002). There are many versions of Romanes, as the Roma have lived in many countries, and English Romanichals speak a dialect of Romanes and English. For Roma people in the UK, their second and public language would be the language of the country from which they have come, and English their third. English language proficiency is very variable, according to place of birth and time spent living in the UK.

- NHS monitoring by ethnicity does not include a category for the Roma. In addition, Roma people may not wish to identify in this way, due to anxieties about prejudice and discrimination.

General issues facing Roma people using London healthcare services:

- Roma people in the UK present with a wide range of health and well-being concerns, as with members of other communities. However, societal and some cultural and historical factors can have a negative impact on their access to, and experience of, healthcare services. Members of Roma communities may be affected by poor diet, obesity and diabetes, as well as childhood hearing impairment (Swanwick et al., 2018).

- The Roma have a history of, and ongoing experience of, prejudice and discrimination, affecting access to services as well as their health and well-being, particularly mental health (Zawacki and Ferranti, 2021). This can include multiple, or intersectional, discrimination (Scottish Government, 2022); for example, older Roma women can experience particular difficulties in accessing appropriate healthcare services.

- Roma people in the UK report experiencing communication difficulties, and problems with interpreting and translation provision, in relation to accessing healthcare services. Where interpreters are provided, they will be speaking in the client's second language, although some Roma people, particularly those who are older, may prefer to speak Romanes. Written materials provided in the language of the country of origin may not be understood, and medical terminology may be unfamiliar, with some words not existing in the Romani language.

- For many Roma people in the UK, particularly older people, a lack of education leaves them with limited knowledge about the available health and well-being provision, routes to services and medical terminology.

- Cultural prohibitions, regarding women's health issues including childbirth, mental health conditions and disability can inhibit Roma people's access to beneficial healthcare services.

- Many Roma people living in the UK continue to experience difficulties relating to securing UK settled status following Brexit (Roma Support Group, 2021a).

UK Government guidance:

- These guidelines may be used in conjunction with **UK Government guidance**, **'Improving Roma health: a guide for health and care professionals'** (2022), available at: https://www.gov.uk/guidance/improving-roma-health-a-guide-for-health-and-care-professionals

Findings from recent research in northeast London:

- **Findings from recent research into the health and well-being experiences of Roma people living in London** suggest some principles that might be used within both the London and the wider UK context, in order to promote positive experiences for Roma people in relation to health and well-being services.

- A recognition of **the significance of language use in the context of healthcare services** provided for Roma people may contribute to improved health and well-being experiences for members of Roma communities. Popular discourse and narrative about Roma people, for example, may be prejudicial or romanticising, or may assume Roma health disadvantages, often in relation to an idea of Roma culture as contributing to poor outcomes. An awareness of what is written about the Roma, how they are listened to, the ways in which they are spoken to and about, and the use of language in the production of materials relating to Roma health and well-being can all contribute to improvements in Roma health and well-being experiences and outcomes.

- The health and well-being experiences of Roma people can be located in relation to **migration and processes of adaptation to life in a new country**. These experiences have many similarities with those of members of other groups (Kapadia et al., 2022), and Roma people are aware of their shared experiences with others. Constructing Roma people as vulnerable or 'hard-to-reach' can contribute to their continuing marginalisation. However, this should be balanced with a recognition of ongoing oppression, exclusion and a culture of silence regarding the health and well-being needs of Roma people.

- **Involving Roma people in the planning of local health and well-being policy and services** provides opportunities for their voices and views to be heard and acted upon. A learning alliance offers a model through which service users, including Roma people, might be consulted, along with people from other groups (Moreno-Leguizamon and Tovar-Restrepo, 2021; Moreno-Leguizamon et al., 2015). Whist a learning alliance might be used to consult with members of a range of Black, Asian and minority ethnic groups, including those from Roma communities, and may offer opportunities for cultural exchange, an exclusive focus on minority groups again carries the danger of marginalisation through 'difference'. Consultations may, therefore, need to be broadened, to ensure that members of all communities are involved in planning healthcare services that recognise diversity amongst all people, and not only those from marginalised and 'othered' communities. Mono-cultural healthcare services, with a one-size-fits-all model, may not be appropriate in all cases and this applies to all people.

- Roma people, in particular women of all ages, carry with them **understandings about the management of health that have been developed within Roma communities over centuries**. An engagement with this knowledge during processes of consultation may be helpful in avoiding imposing a medical model that could prompt the self-exclusion of some Roma people. Again, this principle might be usefully extended to service provision for a wider range of communities.

- In the context of migration, older Roma people may find adaptation to new expectations and experiences particularly difficult. They may need **support with communication, with information, and with ensuring registration with a GP**. Communication difficulties can present significant barriers for members of Roma communities, in relation to accessing health and well-being services in the UK. Interpreting and translation services need to be provided appropriately and in consultation with Roma people, to establish the type and level of support needed, as well as the language to be used. Again, consultation with Roma people with regard to interpreting and translation can contribute to positive health and well-being experiences and outcomes.

- A recognition of **Roma cultural requirements**, in relation to women's health, mental health conditions and disability is necessary. However, this is not just a Roma issue, as Roma people share these needs with people from many other groups, including, but not exclusively, Black, Asian and minority ethnic communities. Cultural awareness training for healthcare practitioners can be helpful but should not reinforce a narrative of Roma people as uniquely different from everyone else.

- Following on from this, it is important to recognise that **culture is constantly changing and adapting to new circumstances**. This includes Roma culture. In this view, Roma people can be seen as inhabiting the modern world, rather than as being caught within an idea of a static, traditional past. Within Roma culture lies knowledge about health and well-being, which can be utilised in the present time. Understandings about health, held by Roma women of all ages, could be included in planning for healthcare provision. Where Roma beliefs about health differ from those of the mainstream biomedical model, an openness towards their ideas and experiences may be fruitful in building positive relationships between Roma people and healthcare practitioners.

- A more nuanced awareness of the health and well-being experiences and needs of Roma people is achieved through **intersectional understandings**, in which positive, as well as negative, factors may intersect. For example, whilst older Roma women may be subject to cultural prohibitions regarding Roma women's health, and exclusion due to a lack of education and communication difficulties, within their communities, older Roma people carry respect and Roma women are seen as knowledgeable about health matters. Younger Roma people, born or brought up in the UK, may have complex relationships with traditional Roma culture but may also be more able to negotiate life in the UK than their parents and grandparents.

- **As an overall principle**, enabling equality of access to services that may be inhibited due to socio-economic factors, including prejudice and discrimination, can be seen as different from assuming a lack of knowledge among people whose culture is deemed to be un-modern.

- Felicity Bonel, July 2023

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