

## **Abstract**

While cancer outcomes in the UK have improved, inequalities remain with poorer and some ethnic minority populations experiencing lower survival rates. Research has addressed Gypsies' and Travellers' cancer related beliefs, experiences and practices as part of wider studies but this is the first study in the UK to specifically focus on cancer. Findings suggest that health beliefs and practices are shaped by historical and contemporary social processes and the marginal position of Gypsies and Travellers in UK society can result in a preference for seeking information and support from within the community. Starting from a health assets perspective, findings indicate that the structure of social relations in Gypsy and Traveller communities could be more widely utilised in health promotion programmes. Developing and extending techniques employed by Gypsy and Traveller Non Governmental Organisations (NGOs) such as community based interventions and the use of lay health advisers, could be an effective method of health promotion by raising knowledge of cancer, engaging community members in preventative programmes, and encouraging earlier access to services.

**Keywords:** Cancer, ethnic minorities, community health, health inequalities, Gypsies Roma and Travellers.

## **Introduction**

Despite improvements in cancer survival rates in the UK, stark inequalities remain. Cancer mortality rates have fallen but a social gradient remains with the poorest 10% of the population under 75 having nearly twice the mortality rate of the wealthiest 10% (Department of Health, 2014). Cancer awareness is lower among men, deprived populations and some Black and Minority Ethnic (BME) groups. This contributes to lower uptake of screening, delayed presentation of symptoms and a higher likelihood of dying from

cancer (National Cancer Equality Network, 2010; Maringe et al, 2012). The Government's Cancer Reform Strategy (2007) emphasised reducing cancer inequalities and developed measures including promoting best practice; establishing a stakeholder forum; providing screening leaflets and audio visual aids in different languages and a helpline with interpreters in over 100 languages. A key plank of the strategy is improved ethnic monitoring (Department of Health, 2014). Although this is problematic and subject to conceptual and methodological critique (Campbell and McLean, 2012; Simon and Piche, 2013), insufficient and inconsistent ethnic recording has hindered understanding of cancer inequalities between and within ethnic groups (Public Health England, 2015). Improved monitoring, particularly of 'hard to reach' groups is necessary to improve outcomes for BME populations and those with the poorest health (Department of Health, 2009; Wilkinson *et al.*, 2009; Aspinall, 2014). Ethnic monitoring of BME cancer patients remains far from ideal with miscoding of about 20% to 35% of ethnicity data of all patients who self-report, while in one study of five local authorities only one had identified gaps in data and knowledge in relation to cancer in BME populations (Fazil, 2018, p. 47).

Monitoring of health is even more problematic with Gypsy, Roma and Traveller populations as the National Health Service (NHS Health and Social Care Information Centre (HSCIC) does not include them in their ethnic monitoring codes. The Traveller Movement has led a campaign to for the inclusion of Gypsies, Roma and Travellers and the late Lord Avebury queried the government's position on this issue in the House of Lords (Traveller Movement, 2014). To date however, there is no systematic large-scale information on Gypsy and Traveller health or of cancer prevalence, use of services or outcomes. The largest health study in the UK to date is Parry *et al.*'s sample of 293 Gypsies and Travellers, which confirmed their poor health (Parry *et al.*, 2004). Qualitative studies of Gypsy and

Traveller health beliefs have noted fatalism around health and illness, and a strong oral tradition that can perpetuate certain health related beliefs and taboos. Poor health is compounded by low levels of health literacy, poor uptake of services and a lack of trust towards health staff (Parry *et al.*, 2004; Van Cleemput *et al.*, 2007; Dion, 2008; Smith and Ruston, 2013; Mc Fadden, *et al.*, 2018). Jesper *et al.* (2008) is one of very few studies to explore issues around terminal illness, healthcare access and palliative care with this population. They found that the extended family play a central role in caring for terminally ill family members; their respondents expressed a strong preference for home based care and had little awareness of palliative care services. Pertinent to the development of tailored health promotion strategies is the authors observation that the closeness of the family coexisted with a need for discretion on the part of the individual, highlighting 'the importance of propriety of conduct in Gypsy Traveller culture' (Jesper *et al.* 2008, p. 161).

The traditional understanding of minority health behaviour has been based in a 'cultural deficit' model that views certain cultural health beliefs and practices as leading to poorer health (Collins, 1995). Sociological accounts of collective health beliefs and practices tend to view these as responses to deeper social mechanisms, with the objective being to understand and explain how those beliefs and practices have developed in different social contexts. From this perspective, the marginal societal position of many Gypsies and Travellers should be the starting point for understanding their health behaviour (Smith and Newton, 2017). Family and communal relations are characterised by 'bounded solidarity', which tends to be inward looking with group cohesion achieved through the trust and norms arising from shared adversities and experiences, such as prejudice and discrimination (Portes and Sensenbrenner, 1993). As a result, Gypsies and Travellers are often

regarded as 'hard to reach' and 'difficult' to work with by health and other professionals (Wemyss, Matthews and Jones, 2015, p. 19). It is from such assumptions that the deficit model has influenced the design of health interventions for Gypsies and Travellers by focusing on the communities problems and needs and how interventions can address them.

By contrast this article proceeds from a health assets perspective. This addresses the individual and community level resources, which can protect against negative health outcomes and/or promote health status focusing instead on the ability of communities to identify problems and develop solutions to health issues themselves (Morgan and Ziglio, 2010). This approach shaped the perspective applied to the research and its aims which were (a) to understand how cancer is conceived of and understood by Gypsies and Travellers; (b) examine the relative roles of family, community and health (and other external) services in providing care and support; (c) consider how the social resources internal to those communities can be utilised and enacted to increase cancer awareness and uptake of services.

This paper presents data from an exploratory study involving four focus groups with Gypsies and Travellers. Exploratory studies are appropriate when there is a general lack of knowledge about an area; to gain understanding of the relevant issues and factors and to develop lines of enquiry for further research (Swedberg, 2018). Given the increasing prominence of community engagement, outreach and layperson strategies for engaging marginalised populations in health services, this article considers how the nature of social relations in Gypsy and Traveller communities can be harnessed to provide targeted interventions and culturally appropriate health information.

## **Methodology**

An exploratory qualitative study was conducted comprising of four focus groups. Three of these took place in the East of England with a total of 18 (16 female and two male) adult English Gypsies (13) and one took place in the South East with five Irish Traveller females. Despite these populations having distinct origins, histories and cultural practices a nomadic lifestyle or heritage and distinctive forms of social and economic organisation, means they share important similarities while marginalisation, prejudice, and exclusion is a common experience of both populations (Cromarty, 2019). Given the interest in exploring the potential of social resources in promoting awareness around cancer, the areas were chosen because both have significant and long established Gypsy and Traveller populations with well established community structures and networks. They were therefore ideal in terms of considering community capacities, assets and the potential for a more active participation movement in cancer programmes and health interventions more generally. A semi-structured topic guide was used, based on issues identified in the literature while probing questions gathered additional information on issues the participants' raised themselves. Participants were purposively sampled by two trained community members who utilised their networks to recruit participants willing to discuss what has been regarded as a 'taboo' subject for many Gypsies and Travellers (Parry, *et al.* 2004, Jesper *et al.* 2008, Smith and Ruston, 2013). Focus groups were held on privately owned caravan sites in the two locations facilitated by the two community members and accompanied by one of the academic team who led the discussion using a topic guide. This covered beliefs and practices surrounding cancer along with experiences and knowledge of informal and formal cancer care and how cancer services could be organised to better suit the needs of this community.

Focus groups lasted between 60 and 90 minutes and were audio-recorded, transcribed verbatim and analysed for emerging themes

afterwards. Transcripts were read separately, labelled and coded by each of the research team through a process of 'investigator triangulation' and a framework of emerging themes were developed by comparing, negotiating and agreeing on the content, as well as the development of new themes or sub themes (Barbour, 2001). Using this approach quotes were assigned to themes; hence the illustrative quotes below are examples of a given theme.

Five main themes emerged from this process:

- Cancer related beliefs and avoidance strategies.
- Health seeking behaviour and the lay referral network;
- Attitudes towards experiences of, cancer treatment and care;
- The role of social networks in supporting cancer patients.
- How cancer services could better meet the needs of Gypsies and Travellers.

Limitations of the sampling strategy relate to it being a self-selecting sample. In this respect the participants may be atypical, though this would not invalidate their experiences and knowledge of community beliefs and practices. It does however indicate the need for more extensive and longer term participatory-fieldwork with those community members for whom the disease is considered taboo and whose views, beliefs and experiences remain unaddressed by the sampling methods employed in this study. An ethnographic approach would have yielded more contextually rich data than that obtainable purely by focus group interviews, with clear implications for a better understanding of community dynamics and processes. As with all qualitative studies a relatively small sample in two areas of England was used and findings may not be applicable to the wider Gypsy and Traveller population. The validity of the findings was checked through comparison during data analysis, respondent validation and by reference to the limited literature available. Ultimately however, there is a need for the inclusion of Gypsy, Roma and Traveller populations in NHS ethnic monitoring data and for

larger scale studies combining survey and qualitative data collection to provide a systematic knowledge base on the health status of this population.

## Results

### *Cancer related beliefs and avoidance strategies*

Discussions surrounding cancer were largely framed in terms of death, even where this was incompatible with real life experiences. Most participants had personal experiences of family members suffering from the disease and many recounted examples of them undergoing successful treatment and recovery. Nevertheless these experiences coexisted with a close association of cancer diagnosis with death, highlighting both the complexity and contradictory nature of health beliefs (Victor, 2005, p. 107).

They'll never find a cure for it, all the research and all that they do...people don't like to talk about it because there's hundreds and hundreds of different cancers and they haven't found a cure for any one of them yet (Focus Group [FG] 3)

Gypsies and Travellers will generally avoid discussing cancer and employ strategies to 'disengage from the stressor or its effects' (Harrington, 2011, p. 311). This is until references to the disease becomes unavoidable due to a family or community member being diagnosed, and then it is described in euphemisms such as '*that disease*' or '*that old cover*' among others.

You talk to any Traveller what would we think. "Oh did you hear such and such one, she's really bad." "What's wrong with her?" "Oh she's got that bad complaint." Even the old women will say it won't they, everybody says, "Oh she's got that bad complaint." People don't say the word cancer (FG1)

Participants explained this type of avoidance behaviour in terms of a superstitious notion of causality, whereby using the word could make the person more susceptible to it themselves (Jesper *et al.*, 2008; Smith and Ruston, 2013).

People don't like saying cancer because it might be jinxing it or something. It's like a superstition thing (FG 2)

We see it as a death sentence, so we see it as something that if we don't hear it and we don't speak it, hopefully it won't happen to us or someone we know (FG 1)

Another form of avoidance is refusing to acknowledge or address possible symptoms, which has implications for when symptoms are presented to health professionals. Participants attributed the tendency to delay medical help as part of a more generalised worldview of 'living for today', but also recognised that it stemmed from historical experiences of exclusion (discussed further in the following section).

If something is going to happen we don't worry about it until it's too late and I think a lot of that comes just from our life doesn't it (FG 4)

Avoidance strategies shape how and when symptoms are acted upon and influence health-seeking behaviour. This is particularly so given the structural properties and cohesiveness of participant's social networks: as one participant pointed out

Though travellers are a small community it's a big community because most of us are related in one way or another (FG 2)



The role that these interlocking networks of family ties and obligations play in shaping health seeking behaviour is explored in greater detail in the following section.

### ***Health seeking behaviour and the lay referral network***

A reluctance to seek medical advice was a prominent theme in the focus groups a finding confirmed in several studies (Parry *et al.* 2004, Van Cleemput *at al.* 2007, Cemlyn, *et al.* 2009). Although participants attributed this to fatalism they also recognised that such reluctance has social origins, attributing it to discriminatory treatment in health care settings and the refusal of some doctors to treat them when they were on the road. Though this was more commonly experienced by older generations, these collective memories and experiences continue to shape attitudes to health care even when participants are resident on caravan sites with access to health services. One lady who had lived 'on the road' for many years and was now resident on a settled site recalled

It's not in our culture to keep running to the doctors, we don't want the doctors. That's because years ago when we used to try and go to the doctor's they wouldn't see you (FG 1)

Information surrounding cancer is sought firstly from immediate family members and then from the wider community or from the network of NGOs and health outreach services run by and for the Gypsy and Traveller community (Carr *et al.*, 2014). The latter has evolved into an important source of advice, advocacy and signposting to health services due to the development of the community sector and the establishment of a number of local and national community groups. Employing Gypsy and Traveller staff has 'greatly extended organisations' knowledge of the communities they serve and the effectiveness of services and outreach' (Ryder, 2011, p.11). While some NHS trusts and local authorities employ dedicated outreach

workers the health outreach workers employed by NGO's 'acts as an intermediary to statutory services that do not provide outreach' (Van Cleemput, 2012, p. 52). These interventions also have the capacity for scaling up and sustainability if integrated into mainstream health services. However the focus of this article is on the structure of social relations within Gypsy and Traveller communities and the community-level assets that are enacted when a community member becomes ill with cancer. The structure of social relations in Gypsy and Traveller communities for example, means that the lay referral system can draw upon a wide network of information and advice, which may detract people from seeking professional advice.

We'd ask family really we'd go to family. Maybe look for someone in the travelling community who'd had that cancer (FG 3)

Because we all come from big families and say if one of my children came to me and I didn't know I'll ask other members of my family and they might not have experienced it but they might know someone who has experienced it (FG 2)

The lay referral system plays a vital mediating role between the individual and health services. Firstly as the primary source of information and advice; secondly in directing the patient to seek appropriate health care and then in its supportive role once the decision to seek medical advice has been made.

Even though we might get that information someone will say, "Well you need to go to the doctor's I'll go with you." (FG 1)

We talk about it and then we go to the experts. We find out what we need to know, what kind of cancer it is. Then we all stick together (FG 3)

The informational, emotional and practical resources available through social ties therefore impact significantly on health seeking behaviour and the routes through which professional medical help is sought (Elkan *et al.*, 2006). The following section discusses the participants' experiences and views of cancer services and care, as a precursor to examining the role of family and social support mechanisms in the provision of care for cancer patients in Gypsy and Traveller communities.

### ***Experiences of cancer care in formal health settings***

Participants generally spoke approvingly of cancer treatment when detailing the experiences of family members who had, or were, undergoing treatment. They noted that medical staff in specialised cancer units exhibit a greater degree of cultural sensitivity than is generally the case in health-care settings when, for example, large numbers of relatives attend to visit sick or dying family members.

In the cancer hospitals they're very good. People are very understandable. Sometimes when death is occurring the hospitals aren't very understandable (FG 2)

The centrality of trust and importance of a 'trusted' health professional in influencing Gypsy and Traveller's propensity to engage with health services and the role of social networks in circulating information on health services and professionals, has been noted in a number of studies (Lhussier, Carr and Forster, 2015; Smith and Ruston, 2013; Mc Fadden *et al.*, 2018).

My sister when she was in there last year she said she's never been treated so well in her life. We met loads of travelling families in there and they was coming up from all over the country paying private to go to that (hospital)(FG 1)

While participants spoke highly of cancer unit staff, they were often critical of the language and terminology employed by medical staff when communicating information to patients and their families. Such complaints are also common among the wider public and can have serious consequences including misunderstandings, a desire to avoid such interactions and increased reliance on information from family and friends (Leonard, 2017).

A lot of the people talk a load of stuff that we don't understand and you come up with a lot of medical things and we don't understand all that (FG 3)

In terms of personal home care services a lack of cultural knowledge by care providers especially with regards to gender based care was highlighted by participants. While this can also be the case in hospital, at home the family have more scope to practice their normal lives at home and provide alternative care arrangements themselves. Describing an incident when a nurse came to their caravan site to visit her mother who was unwell with cancer, one woman recalled

The last resort ever was when they sent that male nurse out...He got to the door and I said to him, "Where you going?", he said "in", I said "You're not", he said "why?", he said "I've got to", I said "Oh no, we're travellers, we don't have men in their washing my mum so out!" (FG 2).

There was a consensus of opinion that personalised care could better be provided at home, with focus group discussions indicating a strong preference for family based care. The following section discusses the role of social support mechanisms for individuals who have been diagnosed with cancer, and the gendered dimensions that support takes.

*The role of social networks in supporting cancer patients.*

The extended family network plays a central role in providing support to community members who are unwell and this is true following a cancer diagnosis. It was clear during the discussions that demarcations between family and community are less distinct than in the general population, meaning that support for the individual concerned is seen as a collective responsibility.

If someone has cancer everybody tends to come; everybody goes and visits (FG 1)

That means when people do get ill they haven't just got one or two people to look after them.

No they've got 20 or 30 (FG 4)

While social, emotional and practical support is provided by the wider community, personal care is performed by family members on a strictly gendered basis.

My mother had grown up daughters so we did the personal care, showering her, bathing her, changing her clothes and when my dad became ill we said to our brothers "right your job is to do his personal care...we'll cook for him, we'll clean the trailer, make the bed but to help him in the shower and help him with your personal care is your job" and they did it (FG 3)

Family members with terminal cancer are generally cared for at home as Jesper *et al.* (2008) also found. Participants were largely

unfavourable to hospice based care and regarded this as an option of last resort or when family based home care is not possible.

If they can move at all they're usually home. The family usually brings them home (FG 2)

I know one woman who went in one [hospice]. They put her in because they lived in a 22 foot trailer, they never had separate bedrooms they never had the capacity at home to care for her (FG 2)

The centrality of family as the primary source of care, a reluctance to seek help from outside the community and a propensity towards seeking information and support from within it were the central features of Gypsy and Traveller health practices (Race Equality Foundation 2008, European Commission 2014). These had been shaped historically and continue to be shaped in their relationship vis-à-vis the wider society, its major institutions and its health systems. These beliefs and practices also influenced and supported participants' views about how cancer services could be improved for Gypsy and Traveller communities, which is addressed in the following section.

### ***Increasing cancer awareness and services access***

Despite the widespread adoption of cultural awareness training as a panacea for ethnic health inequalities, participants were sceptical that this would lead to a significant engagement with cancer services. In spite of better cancer related knowledge and examples of family and friends surviving cancer, a paradoxical theme was that attitudes towards cancer were impervious to external interventions. The key issue to be tackled from the participant's perspectives are engrained cultural beliefs and practices, which themselves are rooted in a lack of information and knowledge.

It's not the outside community the problem it's within. How can you take what's been bred into somebody and take it out and change it? (FG 2)

There's a big ignorance but I'm not sure if they [health professionals] had any training it would change the way Travellers react or the way they go on. I'm not sure it would actually do anything for that (FG1)

Health information in leaflet form or from online sources can be inaccessible due to low literacy levels particularly among older adults. Given the limited effectiveness of these types of health promotion in reaching Gypsy and Traveller communities it is felt that knowledge of available services or attitudes will not change.

Some of us, well a lot of us don't read or write so the leaflets they're doing don't work, you know? (FG 4)

This suggests the need for more innovative forms of health promotion such as DVD's, an approach increasingly adopted by local health authorities and NGOs in recent years (for example NHS Nottingham's (2015) 'Looking after Mandi' health DVD). The fact that participants were critically aware of the internal obstacles to raising cancer awareness and knowledge within their communities suggests a process of attitudinal change, which makes confronting and surmounting those obstacles possible.

There is a preference for face to face interaction in Gypsy and Traveller communities and participants argued that delivering information verbally would be a more effective way of targeting information at this community. As discussed, this approach has been developed and implemented by several Gypsy and Traveller organisations (Friends and Families of Travellers (FFT), 2018; Leeds

Gypsy and Traveller Education (GATE), 2017; Roma Support Group, 2012) and proven more successful than traditional 'top down' models of health promotion based on a deficit approach and implemented by health practitioners. The success of such outreach programmes is also dependent on contextual factors, particularly the extent to which workers are trusted and whether or not the focus of the intervention has been negotiated with the community first (Carr, *et al.* 2014).

What they should do is if you are diagnosed, they come in and they talk to you about it and they tell you what will happen, exactly what the process is going to be, exactly how you might feel about it, what the effect might be on them (FG 4)

Participants argued that delivering information in a form that they understood would increase willingness to access information about cancer and other forms of health advice

We just want the basic information so that we know and also the ways it's spoken. You know if we go in-house we can understand it because we're speaking to someone who speaks the same way we do (FG 1)

Consequently there was a consensus that a fellow community member would be best placed in this role due a generalised suspicion of the wider society and the structure of Gypsy and Travellers' social networks. This means that his/her status can be verified through internal communication channels highlighting the significance of the interpersonal and contextual factors in building trust (Carr *at al.*, 2014).

The only way to change it is to educate people, someone in the travelling community let them have a job of doing it or talking



to people. That's the only way you could do that because it's hard to go outside do you understand? (FG 1)

One middle-aged male participant added that a community member with sufficient knowledge, could be an important facilitator in overcoming initial unwillingness to present to health services and in providing a signposting role.

You know if there had have been another traveller there that my sister could have phoned and said, "Look I've got a lump." It might have made the difference. (FG1)

A frequent source of misunderstanding that arises with medical staff is over what constitutes a family and a tendency for staff to hold a view steeped in the nuclear family model. When consulting with family members it was felt that hospital staff may exclude the wider family network from discussions, and assume it is not an integral part of decision making regarding the patient's care

It's one of the biggest difficulties people have to understand about us, in all walks of life, is how our immediate family is much bigger than most communities. In our community, it isn't just you tell the husband or their parents you have to tell the aunt and the uncle and the cousin because that's our close family, not just your daughter or son or your husband or brothers and sisters, ours is cousins and nieces (FG 3)

Participants felt that tailored programmes of health promotion that mobilised the social resources within the community would bring the greatest benefits. Hence a trained community member with the appropriate knowledge and lived experience of Gypsy and Traveller culture, and who could translate health information appropriately would be the participant's ideal health promoter. These themes are developed in the following section, which considers the policy

application of our findings and the broader implications for engaging marginalised populations in cancer care and preventative programmes.

## **Discussion**

Findings indicate both the role of lay understandings in influencing how symptoms are perceived and acted upon, and the roles of family and community in providing practical, social and emotional support. Lay understandings are an important component of health beliefs and better understanding of how they shape health related behaviour is needed to design tailored cancer care and support services. For Gypsies and Travellers the historical legacy of negative social attitudes, frequent denial of health care, poverty and exclusion manifests itself in a high burden of childhood illness and poor health throughout the life-course (Cemlyn, *et al.* 2009, Lane *et al.* 2014) and is especially salient in shaping present attitudes to health and health services (Newton and Smith, 2017).

While our findings indicate that the close knit nature of Gypsy and Traveller communities does play a role in the transmission of negative cultural narratives surrounding cancer, similar narratives are also pronounced in other close-knit minority communities (Marmot 2006). Many of the shared beliefs and behaviours found among Gypsies and Travellers such as the belief that treatment can make cancer spread; the use of avoidance strategies, a lack of cancer knowledge; scepticism towards 'official' health messages and delayed presentation of symptoms is also higher among some minority ethnic groups and lower socio-economic populations (Allford *et al.*, 2014; Thomas *et al.*, 2005 Elkan *et al.*, 2006). Stage of the disease at diagnosis is a major factor contributing to differences in cancer survival rates (Auvinen and Karjalainen, 1997). Given late presentation and lower levels of cancer survival among low income and some ethnic minority populations, fatalist outlooks may reflect

the social realities facing those populations more than a distinct system of health beliefs. This suggests that the structured sets of social and economic relations that manifest themselves in the high levels of poverty and social exclusion that frame the lives of many members of these populations, are the 'generative mechanisms' (Archer, 2015) underpinning cancer related beliefs and practices.

The idea that structural health inequalities can be tackled through changing attitudes and behaviour at the cultural level has exerted a powerful influence on health promotion strategies. These tend to adopt an educative approach based on providing relevant health information that it is hoped, will lead to the desired behavioural changes (Douglas, 1995). Sheikh and Ogden (1998) note that knowledge of healthy behaviours will not necessarily promote screening attendance if non-attendance is due to fear, avoidance, shame or the belief that health care is ineffective. They argue that to facilitate earlier diagnosis interventions should address not only knowledge, but also individual beliefs and responses as it is these that mediate between health knowledge and behaviour. Andreassen *et al.*'s (2018) study into participation/non participation in a Romanian national cervical screening programme, found that health providers attributed Roma women's low uptake to a lack of knowledge, negligence, low education and erroneous health beliefs. The Roma women by contrast argued that the programme was inconsiderate of the needs, understandings or expectations of the service users or to the social context in which the intervention was introduced. Raising participation among minority groups Andreassen *et al.* (2018) argue, should begin with the building of contact, interaction and cooperation between service providers and potential participants.

Our study of Gypsy and Travellers' cancer beliefs and practices support a wider body of literature that highlight the pivotal roles that social relationships play in engaging marginalised populations in health programmes (Roy, 2011; Yilmaz *et al.*, 2017). Community

outreach activities including the use of lay health advisers (LHAs) have been increasingly employed by Gypsy Roma and Traveller NGOs and are effective tools of health promotion in contemporary societies increasingly characterised by complexity and 'super-diversity' (Meissner and Vertovec, 2014). Social contacts are used more extensively to secure access to information and resources in poorer and marginalised communities, making LHAs particularly effective in socio-economically deprived populations (Dutta, 2011). Health interventions are therefore embodied in the interpersonal relationships between the LHA and community. This is especially significant in communities such as Gypsies and Travellers where there may be distrust towards outsiders and indicates the need for community based forms of health promotion and intervention, rather than those focused on the individual and immediate family.

Findings demonstrate that the social structure of Gypsy and Traveller communities represents an important asset when fostering and promoting LHA led interventions. Social networks are strengthened by geographic proximity with Gypsies and Travellers reporting a higher number of friends and relatives living locally—even in conventional housing—and with higher than average levels of social activity with non-resident family and friends (Iddenden *et al.*, 2008; Smith, 2008). These spatial concentrations promote frequent communication, assisting LHAs to tap into localised networks and to mobilise members; promote and encourage use of health services and interpret health information (Carr *et al.*, 2017). One of the community interviewers noted that despite many participant's claiming that the capacity for changing health behaviour in their communities is limited, the fact that they were willing to discuss what is often a 'taboo' subject among Gypsies and Travellers demonstrates the importance that the focus group participants attach to the issue and the potential for change. Findings indicate the inconsistent, perplexing and contrary nature

of health beliefs and the social processes through which negative and positive cultural narratives are simultaneously sustained. These informal information circuits can also be utilised to counteract pessimistic narratives and disseminate information about risk factors and the importance of early diagnosis in saving lives.

Our findings support a body of work suggesting the potential of community outreach workers in engaging Gypsies and Travellers in health promotion programmes. Acton *et al.* (1997) note that in a programme to increase cervical smear tests among Gypsy women in the UK the most effective health educators were Gypsy women who had previously undertaken the test. Likewise Sussex based FFT has run a successful outreach programme employing outreach workers with remits for particular areas of health (Van Cleemput, 2012, p. 52), while the Roma Support Group in London has run a mental health advocacy project with bi-lingual mental health advocates acting as bridge builders between migrant Roma service users and health professionals (Roma Support Group, 2012). Carr *et al.* (2017) highlight the importance of understanding the nature of social ties in promoting behaviour change through social influence. This is especially relevant in the context of family reputation and taboos surrounding conditions such as cancer, mental illness and drug addiction in Gypsy and Traveller populations (Cemlyn *et al.*, 2009). Recalling Jesper *et al.*'s (2008) observation about the importance of decorum in Gypsy and Traveller families would require a successful LHA to be cognisant of these complex family and community dynamics. Carr *et al.* (2017) emphasise the requisite attributes of those delivering interventions to Gypsies and Travellers to be community knowledge and acceptance by community members; the ability to communicate health information appropriately and to adopt a wider notion of what constitutes 'close family'.

Cobb and Erbe's (1978) seminal study into the social support networks of cancer patients found that they tend to diminish as the

patient's social roles become more limited and he/she becomes progressively isolated. Our findings suggest that this does not appear to hold true with Gypsy and Travellers as providing support to cancer patients is viewed as a communal responsibility and continues throughout the course of the disease, its treatment and outcomes. However the importance and potential of those support systems within Gypsy and Traveller communities is not always recognised or utilised by health care professionals. Cobbe and Erbe's (1978) recommendation that counselling and discussions with health staff and social workers should encompass not only the patient and their immediate family but friends and wider family members, would do much to improve the quality of service experienced by members of Gypsy and Traveller communities in cancer care settings.

Many of the challenges for service providers seeking to improve cancer outcomes for Gypsies and Travellers are similar to those faced when trying to engage other marginalised groups, who are subject to similar socio-economic, ideological and discriminatory pressures. Nevertheless social structures can weigh more heavily on certain groups due to the cumulative impacts of inherited structural conditions, prejudice and marginalisation both in the past and present and in many societies Gypsies and Travellers have long been the ultimate pariah group (Hancock, 1987). This indicates the need for health interventions applied with a scale and intensity proportionate to the level of disadvantage experienced, thus ensuring principles of equality and fairness (central to the social gradient approach) with the need to account for diversity and difference (i.e. effective targeting for different social groups) (Carey *et al.*, 2015). Including Gypsy Roma and Traveller populations in ethnic data collection and developing targeted services in areas with large populations would go some way towards reducing disparities in cancer outcomes.

## **Conclusion**

In an ethnically and culturally diverse society, better knowledge of the health beliefs and practices of minority populations is vital when tailoring health interventions. Our findings suggest that in Gypsy and Traveller populations cancer is largely framed and articulated in terms of death and decay despite evidence to the contrary among family and friends illustrating the discrepant and ambivalent nature of many health beliefs, with positive and negative narratives coexisting. The reluctance to present symptoms to health professionals reflects a wider hesitance to engage with health services and is rooted in the historical legacy of rejection and exclusion. This persists despite participants' holding very positive attitudes towards specialist cancer services. While NGOs represent an important intermediary role between Gypsies and Travellers and health services, day to day support and care is regarded as the family's responsibility and the preferred option over formal care in a hospice or institutional setting. Findings indicate that this population would engage more with cancer services and preventative programmes if this was delivered in an appropriate manner by somebody with the requisite forms of social and cultural capital within the community (Bourdieu, 1986). In the longer term, reducing cancer inequalities among Gypsies and Travellers, may require a more sustained commitment due to a generalised wariness of outsiders intentions towards themselves and their community, a worldview that itself is a product of their past and present lived realities.

## **Ethical Approval**

The study was granted ethical approval from the University of Greenwich Faculty of Education and Health ethics committee. Informed consent was obtained from all participants prior to data collection.

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