

SAGE Research Methods Case Health Submission for Consideration

Case Title

Accessing Young People who Self-Harm as Research Participants

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Sub-discipline

Academic Level

Contributor Biographies

My professional background is children's nursing. I have a long standing interest in the emergency care of children and young people, having practiced, taught and published in this field. My PhD examined the emergency care of young people who self-harm; my thesis adopted a mixed methods approach to examine attitudes towards young people per se and attitudes towards young people who self-harm and the basis of these attitudes amongst emergency care practitioners.

Published Articles

Characteristics and trends of self-harming behaviour in young people.

<http://web.a.ebscohost.com/ehost/detail/detail?sid=3291f6de-a4fa-4d49-9082-60390b1ff546%40sessionmgr4003&vid=0&hid=4109&bdata=JnNpdGU9ZWhvc3QtG12ZQ%3d%3d&preview=false#AN=24223939&db=aph>

Attitudes of emergency care staff towards young people who self-harm: A scoping review
<http://www.sciencedirect.com/science/article/pii/S1755599X13000347>

Attitudes towards young people who self-harm: age, an influencing factor
<http://onlinelibrary.wiley.com/doi/10.1111/jan.12451/full>

Abstract

Historically research pertaining to children and young people involved them as research subjects, to be observed and measured, while views of children and young people have been obtained through parents and carers. However the important contribution that children and young people make within research, by giving their own perspective on the subject under study is now widely recognised, but gaining these perspectives can be challenging. This case study provides insight into the challenges faced when attempting to recruit young people as participants in a study which examined the emergency care young people receive following an episode of self-harm

Learning Outcomes

By the end of the case you should:

- Understand the principles of ethically sound research and apply these when designing/planning a research study.
- Be able to discuss the specific considerations that apply when conducting research with children under the aged of 16 and how these can be addressed
- Consider the circumstances under which children in the UK may consent to medical treatment and debate the implications of this for their participation in research both within the UK and where relevant in your own country.
- Consider the role of gatekeepers in research and discuss their pros and cons when planning to undertake research that wishes to obtain a child or young person's perspective.

Case Study

Introduction

Undertaking research with young people poses unique ethical considerations. This case study draws on work undertaken for my PhD study entitled, “The Emergency Care of Young People who Self-Harm” (Cleaver 2012). My motivation for undertaking the study was two fold; there existed a fairly substantial body of research that clearly indicated that health care professionals (mainly nurses and doctors) have negative attitudes toward patients who self-harm, with much of this research undertaken in hospital accident emergency departments (Saunders et al 2012). Secondly, a study undertaken just prior to commencing my doctoral work identified that the reaction young people received when first disclosing their self-harm influenced how they subsequently engaged with services (Brophy & Holmstrom 2006). Encouraging young people to engage with health services is important as evidence suggests that young people who self-harm are likely to repeat their self-harming behaviours, with an association between self-harm and completed suicide evident. Early intervention is therefore key to reducing self-harming behaviours and preventing suicide (HM Government 2012).

Previous studies examining attitudes towards young people who self-harm did not obtain the perspectives of young people, an important omission as young people have reported that in order to be treated in emergency departments they often found themselves having to disclose their self-harm, some for the first time (Brophy & Holmstrom 2006). Moreover, testimonials from young people about the care received in hospital emergency departments and ambulance service were largely negative, these findings also evident in narratives and wider research (see for example McDougall et al, 2010:175).

On this basis I decided that inclusion of young people who self-harmed was important. Thus the study aimed to measure the attitudes of staff working in ambulance and hospital based emergency services and, using a mixed methods approach, triangulate the attitudes measured with the experiences of nurses, ambulance personnel and young people themselves, accounts of these experiences obtained through semi-structured interviews.

This case study outlines the processes involved in gaining access to young people to enable them to participate in the study, which were lengthy and ultimately unsuccessful. It begins with a consideration as to why undertaking research with young people who are deemed to be vulnerable presented such challenges, and the measures I took to try and overcome this. The case study concludes by reflecting on whether alternative approaches to recruiting young people may have better served my purpose. The research was undertaken in England, thus reference to policy and legislation is orientated to the UK

Overarching Ethical Principles

Guillemin & Gillam (2004) distinguish different dimensions of research ethics as follows:

1. Procedural ethics, concerned with the process of obtaining ethical approval.
2. Ethics in practice, a term used to describe the issues which arise while undertaking the research.
3. Professional codes of ethics, which provide a framework for researchers as they set out a code of practice.

A Note on Professional Ethics.

As a registered nurse in the UK the Nursing & Midwifery Council's (2015) Code of Conduct sets the standards for how nurses and midwives must conduct themselves, while the Royal College of Nursing (RCN), and Royal College of Paediatric and Child Health (RCPCH) provide advice for doctors, nurses and other health professionals on principles of involving children and young people in research.

A Note on Procedural Ethics.

In the UK if researchers wish to access any patient group for the purpose of research, approval must be obtained through the Health Research Authority [HRA] (formerly National Research Ethics Service, NRES). The HRA website provides detailed guidance on ethical principles underpinning research and how to apply for ethical approval in the UK <http://www.hra.nhs.uk/news/dictionary/nres/>, equivalent organisations similarly overseeing research ethics in other countries.

Obtaining ethical approval required substantial time due to the need to provide clear details of all aspects of the study, including data collection tools and all relevant paperwork for recruiting participants and obtaining their consent. While this was a time consuming process, preparing the application provided a focus for my thinking on my study aims and outcomes, the methodology and data collection methods, and likely timescales.

TIP When applying for funded research ensure you build in time to allow for ethical approval processes as they can necessarily, be time consuming

Mishna et al (2004) point out there are three primary principles that underpin the conduct of ethically sound research, these being:

- Respect of the participants and their right to autonomy.
- The research should adhere to the principles of beneficence (promoting participants wellbeing) and non-maleficence (should do the participants no harm).
- Principles of justice.

In order to adhere to these principles and thereby conduct ethically sound research, the researcher must ensure that appropriate measures are taken through consideration of the following:

- How participants are selected, with a sound rationale for a particular groups inclusion.
- How participants' informed consent is sought.
- Measures that need to be taken to ensure the research minimises harm and discomfort, and on balance, brings about good

These principles were applied to decision making and planning in my own study and are discussed below.

Participant selection: Rationale for Including Young People who had Self-harmed.

Deciding to involve young people who had self-harmed in my study meant considering whether the benefit of their participation outweighed any potential costs, due to potential distress. As outlined above, it was evident that triangulating young peoples' experiences of emergency care with those of nurses and ambulance personnel, and reviewing these in relation to the attitudes towards young people who self-harm as measured through attitudinal scales, was a worthwhile study. By exploring the experiences of young people, it was hoped that the research would provide a basis for reviewing and enhancing the provision of emergency care for young people who self-harm. This in turn might encourage a higher level of attendance and engagement with health services, thereby securing, at an earlier stage, appropriate mechanisms for support. On this basis I decided that the potential benefits of participating outweighed the potential cost, that of distress to the young person when recounting their self-harm and associated experiences of attending an emergency department.

Minimising Risk (of distress)

Having determined that the benefit of inclusion outweighed the risk, and that the risk was distress, it was imperative to plan for how the risk might be mitigated. As Guillemin & Gillam (2004) observe, qualitative approaches to research are more likely to encounter the unexpected, due to the data collection methods they employ. They cite the example of a woman who, while being interviewed for a study on experiences of heart disease, reveals that she has been the victim of domestic violence and the perpetrator has also been sexually abusing her daughter. Similarly, Holloway & Jefferson (2000) report how a woman they

interviewed in their study on crime disclosed factors in relation to her childhood, including a violent father, her fear of rape and sexual assault, and her relationship with her ex-husband. These were all private matters that previously the women had not been able to discuss, but the interview(s) proved to be a catalyst, in terms of disclosing these personal concerns and experiences. In both these examples participants reveal personal experiences, which were largely unconnected to the subject area of the research.

I concluded that, as with all research studies that collect qualitative data, the element of the unknown would be a factor, and to that end it was difficult to predict whether a young person may disclose a concern that may require follow-up, particularly as risk factors associated with self-harm are varied but include difficult family relationships and abuse. To this end, I drew on my professional code of conduct and advice from professional bodies, actions taken being guided by professional standards and determined how, if distress occurred, this would be managed.

Managing Distress while Maintaining Confidentiality

Having identified that there was the potential for distress, I addressed this in my application to the ethics committee with the following actions planned:

- Immediate termination of the interview
- Provide comfort
- Inform young person's general practitioner (GP).

Consequently as part of the consent process, young people would be advised that their general practitioner (GP) would be contacted if they chose to participate in the study. However, it is well documented that young people worry about visiting their GP's, with lack of confidentiality, embarrassment and unsympathetic staff cited as some of the reasons (Tylee et al 2007, Gleeson et al 2006, McPherson 2005). This is further exacerbated if the young person suffers from mental health problems, and /or is experiencing suicidal thoughts, suffers from depression or engages in substance abuse, (Rickwood et al 2007), all of which can be associated with self-harm. I was therefore aware that this course of action might be off-putting to a young person and discourage participation in the study.

Decisions about Selection - Justification for Inclusion and Exclusion

There are a range of predisposing factors which increase a young person's risk of engaging in self-harming behaviours, each of which are themselves associated with additional vulnerability, i.e. difficulties in relationships with families and peers, the association of self-harm with alcohol and substance abuse, and the association with depression. As a consequence I determined that I needed to be selective about the young people I might include in the study, and also needed to consider how and when I would approach them.

When planning the study I had determined that the age range for young people who might participate in the study would be 12 – 18 years of age. The lower age limit had been determined on the basis of research evidence from prevalence studies, which indicate that the onset of puberty is associated with onset of self-harm (Hawton et al 2003a & 2003b, Hawton & Hariss 2008). The upper age limit was determined on the basis that in the UK transition

from paediatric to adult health services is generally recommended at 18 years of age (Department of Health 2004, 2008). Nevertheless, while the age range of 12 – 18 in generational terms is narrow, there is a significant difference between a 12 year old and an 18 year old, which had a bearing on recruitment of young people.

Children and Young People and 'Vulnerability'

Medical and psychological research on children and young people has historically been focussed towards those already deemed 'vulnerable' or 'damaged', whereas social science research explores with children and young people their perspectives on what might be considered, their 'normal everyday lives', and as such the children and young people who participate in such studies are 'ordinary children', asked, for example, to give their views on 'quality time', their experience of divorce, their engagement with morality and values, and views on justice and punishment (Prout 2002). The children in these studies were not selected because they experienced divorce, have working parents, or have particular experiences of justice and punishment, they were selected on the basis that they are children and young people. This was not the case for this study; the young people were being invited to participate because they had self-harmed, and thus they were (potentially) more vulnerable than the 'ordinary' child or young person.

Young people who self-harm are viewed as vulnerable thus justification for including them in research studies needs to be made and clearly argued. However, as Alderson (1995) argues, a balance needs to be struck in relation to protecting children from harm while not excluding

them and thereby failing to seek their views, as children and young people, like adults, also have the right to the highest standard of healthcare, to be informed, express their views, and influence decisions made about them (Modi et al 2014).

Identifying Inclusion and Exclusion Criteria

Although there is clear evidence that an episode of self-harm predisposes a young person to further self-harming behaviours, not all young people go on to repeat this behaviour, have psychiatric morbidity or complete suicide (Hawton & Hariss 2008). Moreover my preliminary investigations when looking at the feasibility of undertaking this study revealed that the emergency departments often saw young people who self-harmed on an occasional or one-off basis, and while there were a minority of young people who were repeat attendees and who had an associated psychiatric history, these were comparatively and proportionally small in number. Nevertheless some young people who self-harmed were likely to be more vulnerable than others, and on that basis I determined exclusion and inclusion criteria - see Table 1 & 2.

Table 1. Inclusion Criteria

Inclusion Criteria	Rational for Inclusion
Aged between 12 – 18 years of age.	This is the age group who are initially vulnerable to self harm and reflect the age group associated with above debates in relation to what constitutes a ‘young person’
Attended and discharged directly home from Hospital emergency department	It is possible that these young people may not receive any further follow up, or may be referred to tier 2 CAMH services (service provided by professionals relating to workers in primary care). It is considered important to obtain the views of these young people as it is possible that they will form the largest proportion of young people receiving emergency care (as opposed to the young people accessed via tier 3 CAMH services)
Were conscious on arrival and during their stay in the emergency department	They would be able to recall and recount their experiences
Were either accompanied by, or subsequently joined by, the resident parent(s) when attending the emergency department	To ensure that when communication from the researcher arrives via the post, the parent(s) will have already been aware of their child's attendance
Have given their full informed consent (assent if under 16 years of age) to participate in the study and where appropriate their parents (or those with parental responsibility) are willing and have given full informed consent for them to participate in the study	To avoid coercion and ensure that the young person is fully informed and willing to discuss their experiences.

Table 2. Exclusion criteria

Exclusion Criteria	Rational for Exclusion
Unconscious when initially admitted to the emergency department due to related alcohol ingestion or poisoning from drugs.	Memory of the experience would be minimal and possibly distorted. It would also suggest that the attendance was initially life threatening and thus their inclusion would not be appropriate as potentially may suggest suicidal intent.
Required intensive care and/or admission to a specialist child and adolescent mental health service	Such a presentation would suggest particular vulnerability as the young person is potentially a suicide risk or have an acute manifestation of an associated psychiatric disorder
Any associated child protection concerns.	These cases will be more complex and also indicate increased vulnerability

Informed Consent (and Assent)

The need to obtain informed consent from potential recruits to a research study is a fundamental element of ethically sound research. Informed consent is an ongoing process and involves the following components:

- The provision of information pertaining to the study
- Advising the potential recruits of the potential risks taking part may entail,
- Advising that participants can exercise their right to withdraw from a study at any stage,
- A continually ongoing process both during and subsequent to, data collection.

As Morrow & Richards (1996:94) highlight, *the issue of informed consent dominates discussions on research with children*, with children's age and associated immaturity the basis for these discussions. McIntosh (2002) notes that, in relation to medical procedures, children are the only group, who by law, can have other individuals consenting for them on their behalf, with the same applying to research. In the UK consent in relation to young people is guided by legislation (Children Act 1989, 2004), which has as a fundamental principle that the welfare and needs of the child are paramount, while instilling parents with responsibilities for their child's welfare.

However, there is lack of clarity as to when a child legally becomes an adult and McIntosh (2002) notes that *the law relating to research on children has never been clearly established but children, with sufficient understanding and intelligence to understand what is proposed, should certainly be involved in the consenting process for any research, even though it is their parents who are required to consent by law*. This principle is based on the Fraser Guidelines, a set of principles established following a House of Lords hearing in the case of Victoria Gillick, who had sought assurance that should any of her daughters go to a doctor for contraceptive advice or treatment, no such advice or treatment would be given without her consent, an assurance she ultimately failed to receive. The resulting guidelines provide parameters by which a young person in the UK may consent to receiving contraceptive advice and treatment without their parents consent and are as follows.

- The young person will understand the professionals advice
- The young person cannot be persuaded to inform their parents
- The young person is likely to begin, or to continue having, sexual intercourse with or without contraceptive treatment.

- Unless the young person receives contraceptive treatment, their physical or mental health or both, are likely to suffer.
- The young person's best interests require them to receive contraceptive advice or treatment without parental consent.

The Fraser Guidelines have successfully been applied to other circumstances in which children under 16 may give consent to treatment (Rose 2007), and indeed as Mishna et al (2004) report, there is evidence that children's capacity to consent to participate in research has been underestimated. Based on the principles endorsed in the Fraser Guidelines, young people in the UK aged 16 years and over are considered competent to consent for themselves as an adult (MRC 2004). Those under the aged of 16 may, if the above 'conditions' apply, consent on their own behalf, although for young people under the age of 16 it is generally accepted that parental consent will be sought, with assent also obtained from the young person. However gaining a young person's assent underpinned by parental consent can be problematic where sensitive subjects, such as sexual health, contraception, and adolescent behavioral studies are involved, and there is a duty to preserve confidentiality (Modi et al 2014).

Providing Information

Gaining informed consent requires the researcher to think through potential ethical issues very carefully, so that information can be presented in a way that participants understand while not feeling coerced into participating, both of which present particular challenges when obtaining consent or assent from children and young people. Potential participants need to receive written information through participant information sheets (PIS), which for this study

were devised using a question and answer format and transposed into a leaflet; the PIS varied slightly, with a version for potential participants aged 15 years and under, a version for the parents of those aged 15 years and under and a version for those aged 16 – 18 years. The language used in the PIS for the young people was written using language that was considered age appropriate, while adhering to guidelines set out in good practice guidance.

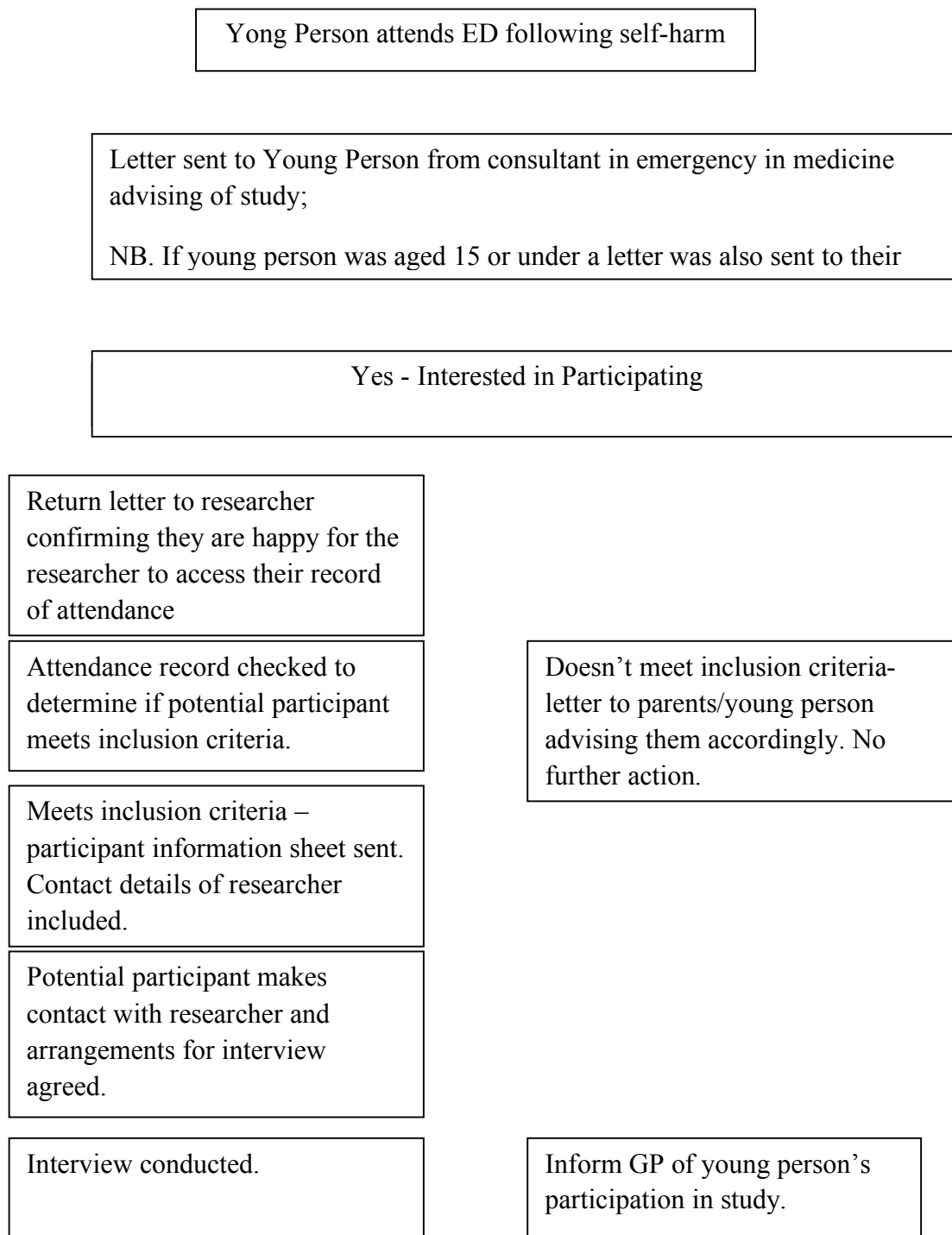
Accessing Young People – Navigating Gatekeepers.

As other researchers have found, because of concerns around children and young people's actual and perceived level of competence, and because children and young people are indeed vulnerable to exploitation, researchers undertaking research with children and young people necessarily encounter an additional layer of gate-keeping. Hood et al (1996) investigated how risks to children are understood and managed by parents and children; the study focussed upon the daily lives of children in and around the home at the ages of three, nine and twelve, living in one neighbourhood. The researchers approached a health centre, community organisations, primary schools and youth clubs in order to gain access to families, but report how they met with a hierarchy of gate-keeping, which ran from *'an organisational level to the parents and finally to the child'*. So for example, when approaching the health centre, the GP's and practice managers identified that they would need to gain parents informed consent prior to be contacted by the researchers. The practice sent out letters to families who met the selection criteria explaining the study with a tear off slip, which stated "I agree" or "I do not agree" to being contacted. As the researchers noted, this placed them at the end of a long chain of negotiation, and most potential participants did not reply. Similarly when approaching children through the schools the researchers had to navigate their way through a

similar ‘chain of negotiation’, which included the head teacher, school secretary and class teacher.

I personally experienced similar gate-keeping difficulties. Initially I had intended to obtain the records of young people who had self-harmed who had attended the designated emergency department, and, based on the study’s inclusion and exclusion criteria identify potential participants who would be sent information about the study. Permission had been gained from the consultant in emergency medicine to access the records. Additionally, in the UK each NHS organisation has a ‘Caldecott Guardian’, who is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information sharing. The hospital’s Guardian had also given permission for me to access young people’s records. However, the ethics committee advised that it was unhappy for me to contact potential participants directly, as they felt this was a breach of data protection. As a consequence I was required to revise my approach to making initial contact with young people, which involved a complex chain as outlined in figure 1. This long chain approach inevitably affected the recruitment of young people, a feature of other research where adult gate keepers have given priority to the adult duty to protect over the child’s right to participate (Hood 1996, Cree et al 2002).

Figure 1: Process for Accessing Potential Participants.



Outcome

Ultimately, too few young people were recruited into the study to enable interviews to take place. Only three young people made contact with the researcher of which only one met the inclusion criteria. Undoubtedly a number of factors contributed to this:

- The long and complex chain between attendance and contact with researcher.
- As a researcher not working in the health service gaining cooperation and engaging staff in the study was problematic.
- Young peoples reluctance to engage with health services generally and to be followed up
- Many young people who self-harm have complex lives and needs and engaging in research is unlikely to be a priority
- As my [then] teenage daughter said to me, *“mum, why would a young person my age want to talk to [an old person] like you in the first place but particularly if they have self-harmed”* – so true.

Reflection

My intention of giving young people a voice in my research study was thwarted for the reasons outlined above. In the UK it is now a requirement to consult with patients and service users as part of the research planning process, as it has obvious benefits, benefits that I was not availed of which could have led to a different outcome.

On reflection my approach to recruiting young people was in itself not ‘young person centred’. I did not have opportunity to consult with young people during the planning phase of the study; had I done so they may have advised me that young people would be unlikely to

engage due to the approach adopted and could have suggested an approach that was more ‘young person centric’.

Rebecca Nyame-Satterthwaite (aged 14) has observed that:

Our input [into research] is very important because we have a unique perspective, which can introduce new ideas, and address issues, which adults may have overlooked. In regards to youth issues, young people will improve research and policies because they have real life experience of problems which affect them... Additionally, youth input will improve the perception of research and policies amongst other young people as information informed by peers seems more reliable, relevant and relatable

The above statement from Rebecca is in the forward to a publication by the UK’s National Children’s Bureau entitled ‘Involving Children and Young People in Policy, Practice and Research’ (McLaughlin 2015). McLaughlin (2015) summarises the benefits of young peoples’ participation in research as follows:

- They offer a different perspective to that of adult researchers
- They can help with the identification and prioritisation of research questions and areas
- They speak a common language and can help with ensuring the accessibility of questionnaires and interviews
- They succeed in getting responses from their peer group in ways that would not be possible for an adult
- They can help with the recruitment of their peers

- They can be very powerful in the dissemination of results
- The experience of participation can be an empowering process, which can lead to increased self-confidence and self-esteem and, potentially, employability.

However, involvement of young people in the design of research and subsequent data collection, otherwise known as participatory research, remains relatively speaking in its infancy (Jacquez et al 2013, Yonas et al 2009, Chen et al 2007), and does not necessarily address the gate keeping difficulties I encountered. This is particularly so when, as was the case with my study, research aims to investigate ‘sensitive’ topics. Dentith et al’s (2009) experiences illustrate this; they report on the challenges they faced engaging young people in participatory research due to gatekeepers and cite how, for example, in a study on sex/sexuality based in Las Vegas, school principals blocked young people’s engagement in the study design process. This was despite parents having given their permission for their daughters to participate, with similar barriers experienced in the other projects the authors describe. They also note how ‘traditional’ approaches to data-collection, such as semi-structured interviews, retain and mirror the wider societal power relations between adults and young people; consequently they moved beyond ‘traditional’ approaches of data collection, for example employing focus groups, thereby enabling and facilitating young people in taking the lead.

While participatory research is viewed as an empowering process, maintaining engagement with young people who themselves lead busy and often complex lives, might be a challenge. Chen et al’s (2007) study employed a framework for participation that was evaluated, and acknowledge that sustaining young peoples’ engagement is a barrier, both due to the nature

of participatory projects, but also due the nature of young people themselves and their development as adolescents.

Conclusions

In order to obtain the perspectives of young people a balance has to be struck between protection from harm, and ensuring their voice is heard. Traditional approaches to research, such as the design adopted for my own doctoral study, while aiming to involve young people failed to gather their voice. Adopting a participatory approach, involving young people in both the design and collection of data may have overcome the problems I encountered.

In part the gate keeping I encountered was due to the study's approach to recruiting young people; using a NHS hospital as a means by which to access research participants posed additional challenges surrounding data-protection and information sharing. A participatory approach could have adopted a more community orientated approach, possibly accessing young people through schools, voluntary organisations or community groups, although permission from parents and gatekeepers within these organisations would still be required. Moreover, participatory research is not the panacea, it still requires engagement with and permission from gatekeepers, and, sustaining the involvement and engagement of young people and keeping them focussed is likely to be more challenging than with adults, given the nature of the developmental phase that is, adolescence.

More experience of participatory research with young people and evaluation of this approach is required, with specific reference to how researchers can overcome the challenges of engaging and retaining young people in participatory research.

Exercise and Discussion Questions

1. In your view, were the ethics committee correct to override the Caldecott Guardian's decision in relation to access to patient data
2. What factors might be influential to young people when considering whether or not to take part in a research study?
3. What are the benefits of a participatory approach when undertaking research into the lives of young people and what strategies might you adopt to sustain their engagement?
4. This study was planned in 2007; social media was in its infancy. Consider whether, given young peoples' prolific use of social media, this could provide an alternative and safe way to recruiting young people to this study?

Further Readings

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Web Resources

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