

Why you should read this article

- To recognise the challenges of public involvement when researching the health of ethnic minority and marginalised groups
- To be able to identify the complex role peer researchers play in building and maintaining trust between their own communities and academic researchers
- To understand why peer researchers' reflections on their involvement in participatory research are rarely heard

Public involvement in participatory research: the experiences of peer interviewers from Roma, Gypsy and Traveller communities

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Abstract

Background A vital component of research is patient and public involvement (PPI). The challenges of PPI increase when conducting cross-cultural research into sensitive subjects with marginalised ethnic minority groups.

Aim To present the authors' reflections on conducting peer interviews with members of Roma, Gypsy and Traveller communities.

Discussion The authors provide examples of reflections on collecting data from a participatory research project that explored Gypsies, Roma and Travellers' experiences of cancer in their communities. They derived the reflections from audio-recorded, post-interview debriefs with co-researchers from the same ethnic backgrounds as interviewees ('peer researchers'). The main challenges for the peer researchers were cultural, linguistic and pragmatic, all fundamentally related to exploring a sensitive health topic through the lens of ethnicity.

Conclusion Peer researchers recognised their role in building bridges between participants and the research team. They did this by establishing a relationship of trust, minimising distress, representing the views of their communities and obtaining data to meet the aims of the project. Peer researchers perform multiple roles to assist in cross-cultural data collection in participatory research.

Implications for practice This article highlights underexplored aspects of peer researchers' work that have implications for the planning and conduct of cross-cultural research with marginalised groups.

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Keywords

data collection, diversity, ethnicity, interviews, qualitative research, research, research methods, study participation

Introduction

Patient and public involvement (PPI) is a major focus of policy and practice in health and social care research. The aims of PPI are multiple, including empowering service-users, increasing representation and improving the quality of research (Involve 2012). There is growing evidence that it has positive effects in research, including improving recruitment in studies and increasing its relevance to service-users (Russell et al 2019).

In participatory research, ordinary people generate knowledge in addressing their concerns as members of society (Park 2006), working alongside academics as 'peer researchers' who explore research questions from the perspectives of their own communities. Involving the public as participatory co-researchers is one of the highest levels of PPI (Involve 2012). However, the extent to which PPI continues throughout a study varies – Jennings et al (2018) suggested that involvement can be inconsistent, once funding has been awarded.

PPI is important when studying the health of ethnic minorities, who are less likely to be included in mainstream studies. Roma, Gypsies and Travellers are ethnic minorities who share a nomadic background and history of oppression, and experience severe health inequalities. Gypsies and Travellers are among the oldest ethnic minorities in the UK, while Roma people from continental Europe have migrated to the UK in the 21st century (Condon et al 2019). Peer researchers from a variety of marginalised and vulnerable groups have collaborated with academic researchers to bring about more equitable and open engagement (di Lorito et al 2017); these groups have included Roma, Gypsies and Travellers (Jackson et al 2016, Smith et al 2020). However, it is complex to involve peer researchers from marginalised groups (Freitas and Martin 2015), particularly when exploring sensitive subjects. Participatory research is well-suited to working with indigenous people as it is collaborative, respectful and reciprocal,

reducing the likelihood of oppression and exploitation (Mitchell 2018).

In cancer research, PPI frequently takes place with the most socio-economically advantaged patients, while men, young people and ethnic minorities are often under-represented (Pii et al 2019). Cancer is a highly sensitive subject for many people, often accompanied by fear and fatalistic beliefs (Licqurish et al 2017, Vrinten et al 2017). Studies of Gypsies and Travellers' attitudes to cancer have revealed cultural taboos, which can extend to avoiding saying the word 'cancer' (van Cleemput et al 2007, Berlin et al 2018, Millan and Smith 2019).

The researchers' persona influences the quality and content of qualitative data they collect (Oakley 1981, Richards and Emslie 2000), so it is important to provide contextual detail when reporting studies. Russell et al (2019) promoted better reporting of PPI, including discussing its challenges and disadvantages. Staniszevska et al (2017) developed the Guidance for Reporting Involvement of Patients and Public checklist, to improve reporting of the effects of PPI.

A research area of developing interest is peer researchers' accounts of their experiences of involvement in studies (Devotta et al 2016). In this paper, we will look in detail at peer researchers' experiences of interviewing, using direct quotes from contemporaneous, audio-recorded debriefs that peer researchers made when collecting data.

Our study

We have reported elsewhere on our study of the views of Gypsies, Roma and Travellers concerning cancer prevention, treatment and care (Condon et al 2021a, 2021b). This study was highly participatory, with members of those communities involved in identifying the research topic, bidding for funding, collecting and analysing the data, and disseminating findings. The findings were disseminated through academic routes

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Key points

- Post-interview debriefs provide an opportunity for peer researchers to reflect on their experiences and themes arising within the data
- Highly developed communication skills are required when peer researchers interview peers
- Shared ethnicity can be a barrier as well as a facilitator to collecting data about a sensitive subject

such as conferences and journal articles, as well as at workshops to which community members and professionals were invited.

We obtained ethical approval from a university ethics committee before collecting any data. Peer researchers carried out between one and 10 interviews each, with two co-authors (JC and DLM) each conducting 10 interviews. More accurate information may be obtained when participants speak in their own language (Liamputtong 2010), so interviews with Slovakian Roma people were conducted in Slovak or Romanes – a language spoken by people of Gypsy heritage – and subsequently translated into English.

Peer researchers ($n=6$) were women and men aged 18-58 years old from the same groups as the participants – Gypsies, Travellers, and Romanian and Slovakian Roma. They were recruited through third-sector organisations, had previously acted as advocates for their communities and were accustomed to working with non-Gypsies ('gorje'). All combined the research with other employment and were reimbursed for their time and expenses. It was important to the peer researchers that the interviewees also received a financial 'thank you' for their time and contribution – they had experience of this not being offered in previous projects, which had made their role harder.

Training consisted of a two-hour session on collecting qualitative data, with a focus on ethics and interviewing skills. This brief training was all that was feasible, given the time restrictions of the project and the peer researchers' busy lives. Field notes from peer researchers were collected as audio-recorded debriefs after each episode of data collection; one peer researcher also voluntarily wrote a reflection after her first day of interviewing. Debriefs were unstructured and focused on issues of priority to the peer researchers, such as the process of interviewing and the themes arising. All the debriefs were conducted in English.

When the debriefs were transcribed, it was apparent that they contained valuable

insights into the role of peer researchers. We agreed to present these in a co-written article.

Peer researchers' experiences Gaining and keeping trust

The peer researchers believed that their ethnicity was an important factor in participants' willingness to share their experiences of cancer prevention and treatment. A Roma peer researcher said: 'Because it was done by myself, then they had trust.'

When the peer researchers explained the project and the research process to participants, they also vouched for the academic researchers and the funder, Tenovus, using easily understandable language. The peer researchers described Tenovus as running charity shops – something with which the participants were familiar – as well as having a mission to raise awareness of cancer. In this way, they formed a bridge of trust between the participants and the researchers.

Confidentiality was important to interviewees and the peer researchers said they used advocacy skills to reassure participants that their contributions would be anonymised. One Gypsy interviewer commented that an interview could seem like a social visit to a friend or family member, but that the audio-recorder symbolised that the conversation would be shared with others. All the peer researchers noted that the participants expressed themselves more freely before and after the interview. One Gypsy interviewer joked that she would have liked to 'break the rules' to reduce inhibitions by switching on the audio-recorder while the interviewee was simply chatting. On another occasion, a peer researcher listened to the whole audio recording with the participant, to ensure they had said nothing they would prefer not to be recorded.

Talking about a sensitive subject

Negative attitudes posed a problem in discussing the sensitive subject of cancer.

The Roma peer researcher commented that the word ‘cancer’ was not something participants ‘easily pronounced or gave the impression of wanting to hear’. This meant she sometimes conducted interviews without mentioning the word, using euphemisms instead. The Romanes translator offered the following insight about the language used: ‘In this Romani dialect, cancer is called “džungali”, which translates as “ugliness, meanness, dirtiness, evil, etc”, or [it is referred to] as “this/that thing” or “this/that sickness”... In this interview, I translated the Romani term “džungali” simply as “cancer”.’

This shows how the original meaning and the work of the peer researcher to overcome cultural barriers can be lost in translation. Linguistic issues are infrequently discussed when reporting findings when research data is translated from the original language used by participants (Alzyood et al 2020).

Strong cultural beliefs about modesty and privacy (Okely and Ardener 2013) made talking about disease difficult, especially when female peer researchers interviewed men. One Gypsy/Traveller researcher said: ‘I think he didn’t like talking to a woman. He agreed to do it because he thought it would be an interesting thing to do... But then he didn’t want to go into too much detail with me.’

Some peer researchers and participants considered it easier to talk to a gorje about sensitive subjects, because shared awareness of taboos led to mutual embarrassment. One researcher struggled with mentioning bowel screening as he viewed it as shameful. Thus, paradoxically, a shared ethnic identity could inhibit as well as promote disclosure – this limitation is underacknowledged in existing research, which focuses predominantly on the positives of peer research (Liamputtong 2007, Condon et al 2021a).

Some participants became distressed during interviews when talking about experiences of cancer in their families. Peer researchers responded to this by offering

them a break (as suggested in training), then continuing if they wished. Most participants did resume the interviews – peer researchers considered this was because they were committed to telling their stories (Box 1).

Using interviewing techniques to acquire in-depth data

A shared cultural background could pose a risk when collecting data because much is understood without being made explicit when members of a close-knit community discuss a topic among themselves. One Gypsy researcher said that to obtain data understandable to the gorje, she asked interviewees: ‘Can you try and explain it as though you are explaining it to someone who doesn’t know?’

When training the peer researchers, we discussed a provisional interview length of around 30 minutes, derived from the lead author’s experiences of interviewing people from marginalised and socially excluded groups. However, it was sometimes difficult for the peer researchers to sustain conversation for this long, with the average interview lasting only 15 minutes.

All the peer researchers said there was a cultural aspect to interviews being shorter than anticipated. First, asking probing questions highlighted that this was an interview, not a social occasion, and bordered on cultural unacceptability. This was exacerbated when talking about a sensitive subject, with peer researchers attempting to strike a balance between minimising distress and obtaining data. One Gypsy/Traveller researcher said: ‘It was still... quite raw with him. He went in as deep as he wanted to, you know? And I didn’t want to push... I didn’t want to

Box 1. Responding to a participant's distress

Gypsy/Traveller peer researcher

‘He did get emotional because there was a close personal connection... he was a typical male, trying to hold it all in, but I could see from his face... so we stopped for a bit... He wanted to continue... to go back over a couple of things that he thought he could add.’

Roma peer researcher

‘After a little break, during which the lady drank water, I reiterated that we do not have to continue. However, the lady herself asked me to resume.’

lose the information we had, like pushing too much... A little bit of information was better than none.'

Secondly, peer researchers said Gypsies and Travellers have a straightforward style of communication. One said: 'With a lot of Gypsies, they tend to be "cut and dry"... They will answer in a cut and dry manner... no matter how much you try and draw it sometimes.' However, participants who were more highly educated, such as a teacher, were considered more willing to talk at length.

Considering the effects of participation

Peer researchers initially had concerns about how participation would affect interviewees. The ethics committee highlighted the issue of potential distress and we made plans to manage this, such as seeking support from a nominated family member and offering a leaflet with helpline numbers.

But after collecting data, the peer researchers decided that participants had enjoyed and benefited from being interviewed. The Roma researcher explicitly stated the value of giving voice to seldom-heard people (Box 2).

One concern for peer researchers and other potential gatekeepers that arose when we were designing the research was interpreting data as being representative of their ethnic group. For instance, a Roma pastor told a researcher that he was opposed to his congregation being involved in the project because he disagreed with participants being selected according to

their ethnicity, saying, 'This is not a zoo.'

Peer researchers agreed with the concept of interviewing community members, but they were also concerned about 'placing' or defining people by their ethnicity (Liamputtong 2010). A Gypsy peer researcher reflected after one interview, 'It may not be 100% true representation of all Irish Travellers because of the differences of being more educated maybe.' Thus, peer researchers critically reflected on issues of sampling and the generalisability of qualitative data.

At a personal level, peer researchers considered they benefited from involvement because they enjoyed interviewing and felt they were contributing to better awareness of cancer in their communities. One adverse effect for peer researchers was being distressed by interviewees' painful experiences of discrimination and racism (Box 2).

Discussion

The experiences of peer researchers, particularly those from marginalised groups, is underexplored in PPI (Pii et al 2018). These reflections are relevant to participatory and cross-cultural research and highlight peer researchers' skills in collecting data (Box 3). Peer researchers are often relegated to the role of 'watching the experts at work' (Bissell et al 2017), but they led on data collection in this study, and used their social and cultural skills to obtain data that met its aims and objectives.

Establishing trust is important in cross-cultural qualitative research. Roma, Gypsies and Travellers are often mistrustful of people from outside their community, particularly authorities and institutions, which lessens their participation in research (Brown and Scullion 2010). It is therefore vitally important to include members of the community in the research team, to reassure participants and encourage openness (de las Nueces et al 2012, Di Lorito et al 2017). Participants were reticent about being audio-recorded, and the peer researchers strove to give

Box 2. Positive and negative impacts of participation

Roma peer researcher

'I could see the positive impact... suddenly, there is someone who is interested to hear their view, to hear about them and their lives, and I think that is the most positive aspect of the whole project.'

Gypsy/Traveller researcher

'I felt really privileged, especially the last person I interviewed, because... he opened up to me.'

Roma peer researcher

'Something resonates with me following the interview [about] experience of racism. She talked about not getting the right treatment or refused a treatment altogether... purely on grounds of her ethnicity, being Roma; [this] evoked the sense of injustice in me.'

reassurances about anonymity. PPI can improve recruitment and raise capacity and capability among peer researchers (Russell et al 2019).

However, it is rarely noted that shared ethnicity can be a barrier as well as a facilitator to collecting data. In our study, peer researchers identified their shared ethnicity as a two-edged sword that could assist in achieving openness in discussing experiences, but also inhibit disclosure. This was linked to cancer being a taboo subject in their communities and thus embarrassing to discuss. In addition, there were cultural barriers to conducting an in-depth interview containing probing questions.

Shared ethnicity provided an entry point to participation, but researchers then needed to use their skills of social interaction to obtain data. Romanian-speaking peer researchers showed ingenuity in conducting interviews without mentioning the word 'cancer', which has powerful negative connotations. Gypsy/ Traveller peer researchers were challenged by gender stereotypes of women not discussing sensitive health topics with men. All peer researchers demonstrated a sophisticated understanding of how to support interviewees to express their views to the extent they wished, while also attempting to obtain high quality and relevant research data.

De Freitas and Martin (2015) commented on the different levels of readiness of people of different ethnicities to participate in research, which relates also to socio-economic status and educational background. In this study, many participants were not expansive about their views or confident about what to say, and peer researchers provided reassurance that their views were valued. For Roma, it was important to speak in their own language.

Peer researchers were aware of their dual role and the need to belong to two camps – the community being studied and the research team – acting as mediators between them both. The pastor's comment about research participants potentially

being 'animals in a zoo' highlights the importance of doing research with people rather than to them (Involve 2012). Minority groups may rightfully be distrustful of a system that overlooks their needs and researchers must build bridges to ensure their inclusion.

Emotional labour was required to obtain the data required and debriefs were a good way of supporting peer researchers to reflect on their multiple roles. In these debriefs, issues not previously considered, such as the inherent barriers of shared ethnicity, were raised. Peer researchers are rarely involved in analysing the data collected in the study (Jennings et al 2018), as they are often no longer involved at that point due to the pressures of time and funding. However, the debriefs gave them the opportunity to identify themes, which became the foundation of data analysis. Their involvement provided assurance that themes were not just a product of academic insights.

Conclusion

PPI is a policy ideal and increasingly a prerequisite for research funding, but there remains a lack of transparency in how it is reported. This article has illuminated the strategies used by peer researchers to collect data about a subject of great sensitivity in their communities, demonstrating their ability to create the trust. When exploring the views of vulnerable and excluded groups, peer researchers perform multiple roles to bridge the gap between the researchers and the researched.

Box 3. Skills used when interviewing peers about a sensitive subject

- » Explaining confidentiality and anonymity
- » Extending trust to the academic team and funder
- » Stimulating conversation
- » Overcoming shared cultural barriers and taboos
- » Being sensitive to participants' cultural expectations of questioning
- » Collecting and recording data relevant to the research's aims
- » Supporting participants if they are distressed
- » Managing one's own identification with participants' experiences – for example, discrimination and racism

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