MS Peer Research Training Programme 2024

Supporting Materials Pack

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Session 1:
Welcome and Introduction to Peer Research

Peer Research Network

What is peer research?

Peer research is a participatory research method in which people with lived experience of the issues being studied take part in directing and conducting the research.

It aims to empower people to affect positive change by participating in research on their own communities.

Peer researchers (also referred to as 'community researchers') use their lived experience and understanding of a social or geographical community to help generate information about their peers for research purposes. They may be involved in assisting with research design, developing research tools, collecting and analysing data, or writing up and disseminating findings.

Peer research can also be referred to as 'user involvement' or 'service user' research when it is conducted together with the users of a specific service to evaluate that service.

Why do peer research?

There are many advantages to adopting a peer research approach.

- **Access to 'less heard' voices:** Because peer researchers identify with the community being studied, they can often connect with people who might be unwilling to engage with professional researchers. Peer researchers can use their networks and relationships to involve people that may not otherwise have been included in research.
- **Empowerment of participants:** Peer research is about conducting research 'with and for' the people affected. That changes the traditional power imbalance of 'outsiders' conducting research.
- **The added value of lived experience:** Peer researchers have their own lived experiences, and that knowledge and inside understanding of the issues being studied can enhance the research.
- **Gathering better data:** When those conducting research have experiences in common with the people they are interviewing, it reduces the risk of misunderstanding and increases the likelihood that the the conversations will be relevant to the people involved. In addition, people may respond more honestly and openly to an interviewer who has personal experience of the issue being discussed, or who they already and feel they can speak with more informally. The delivers higher quality, more nuanced data.
- **Activating communities:** Participatory approaches can create self-critical communities who are invested in their own wellbeing.

- **Benefits to peer researchers:** Peer research can provide valuable work experience and training that may increase peer researchers' employability in the future. Many people gain confidence and self-esteem by participating in peer research and finding that they add significant value to the process. It may also promote social inclusion among groups who often experience exclusion and isolation such as those challenged by stigma or marginalisation.

Community research

We are a not-for-profit tackling societal issues with a collaborative, multi-disciplinary approach.

Contact our team

Social innovation

Involving people from diverse sectors to shape game-changing initiatives.

Find out more

The Young Foundation is the UK's home for community research and social innovation. We bring communities, organisations and policymakers together to shape a fairer future. We are a not-for-profit, driving positive change and supporting collective action to improve people's lives.

MULTIPLE SCLEROSIS (MS) PEER RESEARCH STUDY

PEER RESEARCHER ROLE DESCRIPTION

What is peer research?

Peer research is designed and conducted by people who have lived experience of the topic that is being researched. In this case, that means that you will have experience of being diagnosed and living with Multiple Sclerosis (MS) This study recognises the importance of the insights, skills and expertise that people with MS can bring to the research process. Incorporating those perspectives into the current research will enable a better understanding of and connection to the experiences we are researching.

What will I do as a peer researcher?

As a peer researcher you will draw on your lived experience of living with MS to speak to people from similar ethnic backgrounds who are also living with MS to help us understand how they experience healthcare, what possible challenges and barriers to access they might have faced in order to co-design solutions and interventions.

How you will be involved in the research study

As a peer researcher, you will be expected to participate in the Participatory MS study in the following ways. You will:

- participate in research training on how to undertake qualitative research.
- attend regular meetings with the research study team.
- work with the study team and other peer researchers to co-design and conduct the research study.
- generate interview questions in order to develop an interview guide.
- plan and conduct 10 interviews (up to 1 hour) with Black British and South Asian British people living with MS.
- plan and conduct a focus group session (up to 2 hours) with ethnically minoritised people living with MS.
- organise, categorise and analyse the interview and focus group data.
- assist with planning the public engagement activities related to disseminating the study.
- co-design solutions and interventions based on the findings of the study with the research study team, healthcare professionals and other stakeholders.

Please note that all meetings and interviews can take place face-to-face or online if needed. All face-to-face meetings will be held in fully accessible venues with appropriate parking, access and facilities. If peer researchers require further assistance in relation to attending face-to-face meetings, contact the study team.

How long will the study take?

Peer researchers need to commit from four to ten hours monthly for a period of twelve months.

REIMBURSEMENT ARRANGEMENTS

How you will be reimbursed

It is expected that peer researchers will commit to participating in research training and conducting peer research for a period of 12 months (with an average of 4-10 hours per month). We will aim to work flexibly to support the different circumstances and needs of the people we work with.

You will be paid according to a fixed hourly rate (£40 per hour). You will also be compensated for any incurred travel expenses to research sites if you are able to travel. The following table highlights the honorarium payments that you will receive depending on the task type and time spent. For example:

Task	Estimated time to complete task	Rate
Reading and commenting on a document	30 mins	£20
Attending a research training session	90 mins	£60
Carrying out an interview	1 hour	£40
Facilitating a focus group discussion session	2 hours	£80
Analysing qualitative data	2 hours (per session)	£80
Participating in a dissemination activity	2 hours	£80

Please note that you may participate in other activities that are not listed in the table above.

COMMUNITY **TOOLKIT**

A guide to working with universities on research projects

'I cannot give you the formula for success, but I can give you the formula for failure which is: Try to please everybody.'

Herbert Bayarde Swope

This guide was written by members of Thrive, a community organisation based in Stockton-on-Tees. It is based on their experience of engaging and working with staff and students of Durham University. We hope that it will offer some guidance to other voluntary sector organisations or community groups about the ways to engage with universities, from first contact through to collaborative partnerships.

Photo: by Gavin Duthie, courtesy of Beacon NE

beacons for public engagement

Newcastle University

Durham University

LiFe

BEACON North East

Why work with universities?

Universities exist to share knowledge and they house expertise in a huge range of subject areas. They can also have useful resources such as funding and facilities and can act as a broker to other organisations and businesses.

'Thrive had funding for a Sustainable Livelihoods Project which needed researching. We could not afford a consultant so we asked the University of Durham to help. One phone call was all that was needed and we were up and running. Usually the university asks the communities for their involvement in studies and research, we just switched it round – never be frightened to ask is our motto.'

What are they after?

Universities are experienced in seeking and securing community involvement, however, they are coming round to understanding what this should actually mean – an equal partnership.

Universities now recognise – and increasingly value – 'experts by experience'. Communities are well placed to offer expertise on a range of issues and can help shape and influence research so that it solves real problems and makes a difference to people's lives. Communities have a wealth of knowledge, resources and material which universities can draw on.

'Local residents know the area, the people, the problems, the good things, the highs and lows of living in the area.'

Photo: courtesy of Thrive

How do we get started?

Like any collaboration, you must know (or at least have an idea of) what YOU want to get out of a partnership. This might change over time, but there should be clear mutual benefits at the outset.

Universities can appear to be daunting places but hold tight – if you are clear about **what you are doing** and **what you want** then you are halfway there already!

The Practical:

- **Timescales and costs**

The costs of the study should be agreed before any work starts. Finalise who is responsible for what and have it in writing. The length of time for the study, research, evaluations and final write-ups should be agreed by all.

- **Expenses**

Volunteers should receive all out-of-pocket expenses; this should be factored in at the agreement stage. A breakdown of volunteer time should give an idea of the expense claims to be expected for the whole study or research.

- **Time management**

Volunteers are passionate, and usually do more than expected. This can be very helpful but can drain a person when they have other things to do in life. This can discourage them and they give up because the burden of work can be overwhelming. Volunteers' workload should be monitored and managed.

Photo: courtesy of Thrive

'Thrive had the help of Durham University medical students to help us undertake a Sustainable Livelihoods research programme. The students helped us in interviewing households in poverty and this counted as part of their studies. Thrive activists were later invited by the University to become part of a co-inquiry action research group that was studying community–university collaborations. This worked extremely well for both parties as we learnt a lot from each other.'

The Principles:

- **Do not do for people what they can do for themselves**

You do not help anyone if you're struggling to do the work of five people – everyone taking responsibility for their own actions creates a culture where all are considered equal and those taking part gain confidence and most importantly, they have ownership of the solutions!

- **Do not promise what you knowingly cannot deliver**

Engaging in a partnership where you knowingly fall short of the requirements or capacity needed is totally unacceptable. More respect is earned when you are totally honest. Remember, this relationship is built on trust, working together knowing the capability of each other should be a given.

- **Have confidence – your opinion is valuable**

You bring a fresh pair of eyes, ears and thinking to the traditional academic world and that is greatly needed and valued. Humour, enthusiasm and a passion for the cause or issue are the most important qualities to take to any collaboration. Redefine your understanding of expertise – it isn't always granted in certificates or letters, it's experience of an issue, a passion for a cause, a commitment to change!

'We discussed our project with the University and figured out what our funders wanted. Knowing what you want can be quite different to what the funding partners want. With the help of the University, we drew up our questionnaire so we understood it and could easily communicate it.'

Photo: by Gavin Duthie, courtesy of Beacon NE

'In our first meeting of a co-inquiry group with academics we couldn't wait to get out for a break because we didn't know what was being said. We stood there laughing at each other because we were totally bemused by what we had just sat through. We made a pact to say something when we rejoined the meeting. We did just that and asked the academics to speak in plain English, and they did. Now we all understand each other and if anybody slips into academia speak (that's what we call it!) they are asked to revert to plain English!'

Other things to consider

- **If you don't understand what is being said – ASK!**

Never be afraid to ask if you don't understand something. Ask for clarification or a definition if it's a term you have never heard before. Likewise, be patient if you have to explain terminology from your experience or sector to someone, we adopt our own language and collaboration is about finding a common language. Set ground rules for terminology and be sure everyone understands what is being discussed.

- **Keep focused – goalposts can be moved…**

Keep to the issue you are discussing. Tangents can waste time and you should never underestimate the value of your time and that of others contributing.

- **…but have patience – some answers don't come easy!**

Everyone else may be discussing theory or last year's research findings but it could still hold valuable information for you to hold and take forward. Take time to consider all ideas and concepts and give everyone enough space to reach their own conclusions before sharing.

- **Persistence – it may be over your head at the beginning**

Do not give in at the first hurdle. Research can be slow and you may have to be willing to both learn new things and teach new things! Everybody has to learn, and willingness for knowledge is what the University is about. Build on that relationship and feed your passion.

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For more details of the Thrive collaboration with Durham University and other toolkits and case studies in this series, see:

www.beaconnortheast.co.uk

www.durham.ac.uk/beacon/socialjustice

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Session 2: Introduction to Qualitative Research Methods Interviews and Focus Groups

Medical Teacher

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Twelve tips for conducting qualitative research interviews

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TWELVE TIPS

Twelve tips for conducting qualitative research interviews

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ABSTRACT

The qualitative research interview is an important data collection tool for a variety of methods used within the broad spectrum of medical education research. However, many medical teachers and life science researchers undergo a steep learning curve when they first encounter qualitative interviews, both in terms of new theory but also regarding new methods of inquiry and data collection. This article introduces the concept of qualitative research interviews for novice researchers within medical education, providing 12 tips for conducting qualitative research interviews.

Introduction

In medical education research, the qualitative research interview is a viable and highly utilized data-collection tool (DiCicco-Bloom and Crabtree 2006; Jamshed 2014). There are a range of interview formats, conducted with both individuals and groups, where semi-structured interviews are becoming increasingly prevalent in medical education research. Qualitative interviews afford researchers opportunities to explore, in an in-depth manner, matters that are unique to the experiences of the interviewees, allowing insights into how different phenomena of interest are experienced and perceived. Considering the relationship between participants and researchers and the emphasis on the exploration of human phenomena, interviews have traditionally been a data-collection method linked with qualitative research and the naturalistic paradigm (Côté and Turgeon 2005; Halcomb and Davidson 2006).

In medical education, many researchers have a background in health care professional backgrounds, and although subjects, such as interview techniques and history-taking are included in medical, nursing, and other health professional curricula, the acquisition of interview skills for the purpose of collecting research data is not generally addressed in the broad spectrum of health care professional education. Consequently, making the transition from working as a health care professional to conducting medical education research involving qualitative research interviews presents a number of challenges (Hodges and Kuper 2012; Varpio et al. 2015). Not only does the new discipline present challenges in the form of engaging with new types of theoretical knowledge, often presented as learning theories, but novices to medical education research will undoubtedly encounter a range of new methods of inquiry and data collection, including the qualitative research interview (Laksov et al. 2017). Furthermore, there are few guidelines relating to the practice of conducting qualitative research interviews. Brinkmann and Kvale (2005) argue that one of the challenges of conducting interviews is that they are carried out under the naïve assumption that the researcher wants to achieve understanding through dialog and discussion. Interviews should not be conceived as informal chats with interviewees; instead they are data-collection instruments which can be used to penetrate a number of research questions. Consequently, given the emerging position of interviews in medical education research, we identify the need to articulate 12 tips for conducting qualitative research interviews.

The tips presented below borrow insights from our own experiences as qualitative researchers as well as from the extensive literature on qualitative research methods. The tips may be more useful in different phases of the interview, some tips may be relevant during the planning phase, others while conducting interviews, while others still are most relevant after the interview.

Tip 1

Identify when qualitative research interviews are appropriate

Qualitative interviewing is a data-collection tool that is useful in a range of methodological approaches and may therefore be applied to address a number of research questions. However, qualitative research interviews are preferable when the researcher strives to understand the interviewee's subjective perspective of a phenomenon rather than generating generalizable understandings of large groups of people, for example, the qualitative interview may lend itself well to exploring a patient's experience of illness, or a clinician's conceptions of learning in the workplace. As such, a study applying qualitative interviews holds the potential to give voice to minorities and groups in society that may not be heard elsewhere (Reeves et al. 2015). Moreover, one should consider the ethical dimensions of taking up time from

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interviewees and therefore only include as many participants as needed in the research project and who may have insights or experiences of the phenomenon in question.

Tip 2

Prepare yourself as an interviewer

The importance of accurate preparation on behalf of the interviewer should not be underestimated and includes conceptual and practical preparations (Brinkmann and Kvale 2005; Brinkmann 2014). Successful interviews start with careful planning that considers the focus and scope of the research question. Some background reading of the literature concerning the subject area as well as how to conduct qualitative interviews and the specific scientific method you are applying will be necessary in the further development of your research question(s) and it will additionally facilitate the construction of an interview guide.

When preparing for qualitative interviewing it is important to be familiar with the data recording equipment being used. The venue of the interview should also be considered as it may affect the data collection. We recommend interviews be conducted at a time and place of the respondents' convenience, in a comfortable setting, free from any potential disruptions and noise. In most cases, you will need formal ethical approval. However, you will always need your interviewees' informed consent (Illing 2014).

Tip 3

Construct an interview guide and test your questions

Conducting a qualitative research interview means that you may be asking your interviewees to reflect on matters that are potentially important to them, in some cases even life-changing. The phenomenon of your interest might be important professionally, or you may be interviewing participants on how they experience illness or the loss of a loved one. Therefore, you should develop your interview guide in advance and conduct at least one test interview. By conducting test interviews the novice researcher gains skills prior to embarking on data collection. These test interviews may be undertaken with peers or volunteers. They furnish the researcher with an opportunity to explore language, the clarity of the questions, and aspects of active listening. The style of the interview is essential for creating a noninvasive and open dialog with interviewees (Krag Jacobsen 1993). Avoid using esoteric jargon in your research interview questions and instead adopt layman's language when possible.

Qualitative interviews may be more or less open or structured. An unstructured or semi-structured interview guide may include only one or a few predetermined questions allowing the interviewer to explore issues brought forward by the interviewee. It is important that the interview guide aligns with the methodological approach (Laksov et al. 2017). By contrast, a structured interview guide usually includes predetermined questions posed in the same way to all interviewees with the purpose of eliciting responses to the exact same phrasing. In medical education, semi-structured interviews are often applied, meaning that the interview guide includes a number of predetermined questions (typically 5–15 questions) but the interviewer can probe, in order to dig deeper, into the interviewees' responses through follow-up questions (Lingard and Kennedy 2010). It is usually a good idea to open the interview with a few "easy" questions to make the interviewee comfortable and to familiarize him/her with the subject of the interview. A few examples are: "Please tell me, how long have you been working here?", "How did you first become involved in teaching?" or "Why did you want to become a nurse?" Further into the interview, questions like "In your opinion, what signifies a skilled teacher?" or "How have you experienced the work load in your current workplace?" are more likely to be answered considerately as opposed to if they were posed as the first question of the interview. A question like "Is there anything more you would like to add?" can be a suitable closing question.

Tip 4

Consider cultural and power dimensions of the interview situation

An assessment of the cultural dimensions as well as power dimensions is necessary prior to the interview (Nimmon and Stenfors-Hayes 2016). Such an analysis could entail a consideration of what the interview situation affords and what obstacles are likely to occur. People are cultural beings (Rogoff 2003) and may have different expectations of the interview situation. Some people may view the interview as a difficult or invasive situation, and some interviews may require a third person to sit in, either as an interpreter or as someone who is culturally sensitive to the interviewees' situation. The test interview outlined above may reveal such challenges. Medical teachers interviewing students need to be aware of both explicit and implicit power relationships and be conscious that students are not trying to comply with expectations of providing, what is perceived to be, a correct response. Similarly, a student interviewing teachers may involve and mirror a power relationship and would require careful consideration in advance.

Tip 5

Build rapport with your respondents

Building rapport and establishing comfortable interactions in the qualitative interview situation is very important and is preferably done well in advance of the interview, but also during the interview itself. A challenge when conducting interviews is that there may be little time in the interview situation to build trust (DiCicco-Bloom and Crabtree 2006). Therefore, you should draft a short summary of your research project, written in layman's terms, to send to your interviewees prior to the interview as a way of informing them of what to expect will be talked about in the interview and why it is an important topic to discuss.

Rapport is also crucial during the interview enabling the respondent to provide a rich and detailed account of the experiences at the heart of the study. Key to building rapport is a sense of proximity. If you already know your respondents, then it may be easier to build rapport; otherwise, this task may be more difficult. One way of building rapport is to approach interviewees with an open and curious attitude, stating specifically why you are interested in

their specific point of view (Krag Jacobsen 1993; Schoultz et al. 2001; Bell 2014). A question like "Please tell me about your interest in … ?" is likely to be understood as less threatening than "What rules and regulations do you follow when … "

Tip 6

Remember you are a co-creator of the data

In qualitative research, the researcher is the prime instrument of data collection. Consequently, the interviewer needs to be reflexive, conscious, and aware about how his or her role might impact the conversation between the interviewer and interviewee. In the qualitative research interview, we argue that the interviewer should not be viewed as someone contaminating or biasing the data, but rather as a co-creator of data together with the interviewee, where the interviewer's previous knowledge may play an important part in understanding of the context or the experiences of the interviewee. As such, the interviewer is not a passive player in the interview, but an instrument using his and her abilities, experiences and competencies in the interview situation (Lingard and Kennedy 2010). For example, an interviewer who is also a clinician may use his or her knowledge about the clinical environment and invite the interviewee to discuss clinical issues more in-depth than if the interviewer was unfamiliar to the clinical context. Therefore, we urge interviewers to make use of their background, albeit, in a considerate way.

Tip 7

Talk less and listen more

Inexperience as novice interviewers may result in the interviewer being overly active in the conversations. Due to nervousness in such situations, or a lack of experience, the interviewee may end up filling in blanks and driving the conversation in a certain direction without being aware of doing so. Interviewers may need to talk less and allow for silence to act as the catalyst that will drive the conversation forward. Actively listening to the interviewees means respecting silence and identifying such silent moments as an opportunity for ongoing reflection. Interviews on subjects that have profound meaning for interview subjects may prompt deep reflection on behalf of respondents. Thus, remain open and honest, maintain interest (Bowden and Walsh 2000; Seidman 2013), listen more, but also listen actively (Giger 2017).

Tip 8

Allow yourself to adjust the interview guide

Adjusting the questions after the initial interviews allows the interview guide to be fine-tuned during the interview process. Some questions might turn out to be misunderstood, others to be irrelevant or outside the scope of the research question. In one of our own studies, for example, the question "How do you experience the atmosphere here?" was understood by students as a question about the physical environment and the quality of the air, while the intention of the interviewer was to gain insight into the social environment in the clinic (Liljedahl et al. 2015). So be attentive, listen to how your interviewees respond, and reflect on whether your questions are being understood in the way you intended. During an interview, follow-up questions can help probe how your questions are understood. Also, be courageous and make changes in the interview guide before the next interview when necessary.

Tip 9

Be prepared to handle unanticipated emotions

In the field of medical education, we sometimes engage with research topics involving illness and death or interviewees' own experiences of e.g. harassment, stress, failure, or interviewee's experiences of students with mental illness. These and many other topics may evoke uneasy emotions in the interviewee, which he or she previously might have been unaware of. Therefore, the interviewer must be sensitive to the interviewee's reactions when sharing experiences on certain topics. Sometimes interviewees will be capable of handling these emotions themselves, but at other times you, as an interviewer, will need to take action to protect your interviewee (Varpio and McCarthy 2018). This might involve interrupting the interview and guiding the interviewee to appropriate assistance. Invite the interviewee to bring up issues of the topic that are important to him or her, and always end the interview by asking the interviewee if there is anything they would like to add regarding the topic of interest in the interview.

Tip 10

Transcribe the interviews in good time

Once the data has been collected, the process of data transcription commences. Although rarely explicitly defined, transcription can be described as the process of reproducing spoken words, such as recorded data from an interview, and converting it into written form so the data can be analyzed. The most common form of transcription in qualitative interviews is verbatim transcription, which refers to the word-for-word reproduction of verbal data, where the written words are an exact replication of the audio-recorded words (Poland 1995). Transcribing data from qualitative interviews is very time-consuming. For novices, initial transcription may require as much as four to eight hours of transcription for each hour of recorded data. Furthermore, the process yields vast amounts of material which must be iteratively scrutinized and waded through when analyzing the data. It is easy to think that transcription is a somewhat straightforward conversion of the spoken word into written word. It is important to consider pauses, giggles, and other cues offered by the interviewee as markers for important events in the interview. These cues may need to be acknowledged in the transcription process. During the transcription process errors can creep in which can be the result of different factors. Consequently, steps need to be taken to check the quality of the transcription. Many investigators choose to transcribe the qualitative interviews themselves even though that is time-consuming and arduous, as it offers great

benefits in terms of getting to know the data. When doing so, we recommend researchers transcribe the interview as soon as possible after completion. Doing so allows the researcher to start identifying analytical structures and find similarities and differences between different interviewees' experiences.

Tip 11

Check the data

As part of ensuring trustworthiness in qualitative data-driven explorations, member checking, also known as respondent validation or participant validation, can be used. Member checking is a method of returning an interview transcript or debriefing the analytical results with participants for agreement (Lincoln and Guba 1985; Creswell 2013). Our experience suggests that this process offers novice researcher a good opportunity to check the quality of the data. As such, member checking may act as a sounding board and a way of checking that one has understood the reported responses of the respondents, especially when it comes to picking up subtleties such as irony, emotions, silences, or other gestures (Birt et al. 2016; McGrath et al. 2016). However, some researchers recommend caution with reference to member checking, as there may be some potential drawbacks such as conflicting views on interpretation (Angen 2000; Morse et al. 2002; Varpio et al. 2017).

Tip 12

Initiate analysis early

One of the main difficulties with qualitative research is that it very rapidly generates a large and cumbersome amount of data, often leading to hundreds of pages of transcribed text. Miles (1979) has depicted qualitative data as an "attractive nuisance"; it has attractiveness due to its richness, but effort is required to find analytical paths through that richness. Therefore, you will need to think about the analysis of data before conducting all the interviews. The nature of the research question(s) and how you go about the analysis will determine the depth, quality, and richness of the performed interviews. Hence, we advise that the analysis of the material is not left until all interview data has been transcribed. Procrastination of data analysis may give the investigator the impression of facing a monumental task; meanwhile, an advantage of starting the work soon is that early thoughts about the analysis allow the investigator to become more aware of emerging categories and themes.

Summary

The qualitative research interview is a powerful data-collection tool which affords researchers in medical education opportunities to explore unknown areas of education and practice within medicine. This paper articulates 12 tips for consideration when conducting qualitative research interviews, and outlines the qualitative research interview in general terms. We acknowledge that certain methodologies might demand alternative procedures than those described above. Although the 12 steps above are ordered sequentially, the qualitative interview, as a rigorous data collection tool, requires an iterative and reflective working process in order to best serve its purpose.

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The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Session 3: Understanding Research Ethics

The UK GDPR

A step-by-step guide to helping researchers comply with the requirements of the UK GDPR

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Step-by-Step compliance with the UK GDPR

When you start a research project that involves collecting information from people - for example via a survey, through interviews, in focus groups or via video recordings - then these questions can help you to comply with data protection legislation in practice.

Will the research project collect personal data?

The first consideration should be whether the project needs to collect information that would be defined as personal data. If not, then do not collect it. If the research does not collect personal data, then data protection legislation will not apply. It is still good practice to develop a data management plan that documents how data will be handled and stored. If you do collect personal data, until the data are anonymised (and the act of anonymisation itself), the information falls under data protection legislation.

Will the research project collect any special categories of data?

If so, then besides the legal basis for processing personal data, an additional condition to permit the legal processing of this information will be required, for example explicit consent or research and archiving purposes. Again, identify why the project needs to collect this information and make sure to communicate the conditions clearly to research participants.

Will you need to conduct a Data Protection Impact Assessment (DPIA)?

Universities/institutes may require a DPIA to be conducted before a research project is undertaken. The first port of call for researchers will be to identify the local rules and requirements.

Under the UK GDPR there are certain circumstances where a DPIA must be undertaken. These include, for example where new technologies are being used and this is likely to result in a risk to rights and freedoms of a data subject or where large-scale processing of special categories data is being done.

Who will be the data controller for the research project?

If personal data are being collected the researcher needs to identify who will be the data controller for the collection, storage and handling of the data. This is unlikely to be the researcher themselves and, in most instances, will be the researcher's university or institute.

Will the research involve collaboration with other partners who will have access to the personal data collected?

If yes, it will be important to identify whether they will be joint controllers of the data or data processors. It will be crucial to ensure data sharing agreements are in place, and where necessary a processor/controller agreement.

What legal basis will be used for processing the personal data in a project?

An assessment will need to be made about the most appropriate processing ground to use for each research project.

There are three grounds that appear most applicable for research: consent, public task or legitimate interest.

If you are using consent as the processing ground, it is crucial that this is distinguished from consent for other ethical and legal purposes, and that participants can withdraw their consent for processing personal data (this is different from the right to withdraw from the research). If public task is used as the processing ground you must ensure that your university or institute is classified as a 'public authority', and that the research will be in the public interest. If you are using legitimate interests as a processing ground, a Legitimate Interest Assessment should be undertaken. This will need to identify the legitimate interest being pursued, demonstrating that personal data processing is necessary to achieve this, and this is being balanced with the rights and freedoms of the participants.

If the project is collaborative with other data controllers it is vital that the controllers work together to discuss and identify the most appropriate processing ground. This is the case if the project spans various EU Member States, as each country has different rules on the use and appropriateness of specific processing grounds. This can mean that, for example in one Member State public task is the appropriate processing ground, yet in another State it is not.

If the project will involve collaboration with the private sector, it is important to consider this when deciding on the most appropriate processing grounds, as some processing grounds will not be applicable to a private entity (e.g. public task).

Which data subject rights apply, and which will be exempted?

It will be important to identify the rights that participants will have and which, if any, will be derogated (exempted). Remember that you do not have to remove any of the participant's rights. Where participants' rights are going to be removed it is crucial that they are informed of which rights will be removed and on what grounds, before they take part in the research. Note that the rights that can be removed from participants will depend on the processing grounds chosen, and what is set out in the national legislation.

What information needs to be communicated to participants?

The information that needs communicating will be influenced by which processing ground is chosen. Broadly, participants should be informed about:

- How any personal data collected about them will be used, stored, processed, and transferred.
- Who the data controller is (and their contact details), the legal ground and purpose of the processing.
- Who will be the recipients of the personal data.
- The period of retention and their rights (including that they can complain to the Supervisory Authority).

We see two primary ways of communicating this information to participants:

- Through an information sheet of the research project.
- By referring participants to information on the processing of personal data explained on an institutional webpage via a Privacy Notice; an example is available for the European Social Survey.

How and where will the personal data be stored?

Personal data should be treated with a higher degree of care than non-personal data, and therefore careful consideration is required of where it is to be stored.

For example, where possible, cloud storage should be avoided, the personal data should remain within the UK, and encryption should be used alongside access controls being applied

to the information, so that only those that need access to the personal data have access. In addition, where appropriate, researchers should pseudonymise or anonymise personal data or remove the personal data and store it separately.

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We are supported by the University of Essex, the University of Manchester, UKRI through the Economic and Social Research Council, and Jisc.

Participant Information Sheet

Title of Research Study: Participatory Research into Minoritised Patient Experiences of MS Care

Chief Investigator: Dr Alison Thomson

IRAS: 327170

We would like to invite you to participate in a research study. You can choose to participate or not - it's entirely up to you. Before you decide, it's essential that you understand the purpose of the research and what it involves. Please read the information provided carefully and ask us any questions you may have to help you make an informed decision. You can also talk to others about the study if you wish.

What is the purpose of the study?

This study aims to understand the experiences of people with Multiple Sclerosis (MS) who identify as British South Asian or Black British.

We will do this by talking to people who have MS through interviews, focus groups, and co-design workshops.

The study will be done by a group of researchers from Queen Mary University of London (QMUL) who will be working together with trained "co-researchers." These co-researchers are individuals from British South Asian or Black British backgrounds who have MS themselves.

What would taking part involve?

Interviews:

As part of this study, you will participate in an interview that will last approximately 1 hour. You can choose to do the interview online through Microsoft Teams or Zoom, over the phone, or in-person based on your personal preference. We will follow current COVID-19 government guidelines to ensure your safety. The interview will be sound recorded with your consent.

Focus group:

We would also like you to participate in a focus group that will last approximately 2 hours. There will be comfort breaks scheduled throughout the session. The focus group will have one researcher and one co-researcher who will ask questions, listen, and take notes. There will be 6-8 other people with MS participating in the focus group, and we will let you know if their carers will also be present.

You can participate in the focus group online or in-person. The session will be recorded with your consent, and you don't need a camera or computer to join the online focus group. Instead,

you can dial in using a phone. To ensure privacy and confidentiality of other group members, you will need to have access to a private space or use headphones during the online focus group.

Participation in the focus group is voluntary, and you do not have to take part if you do not wish to.

Co-design workshop:

You are also invited to participate in three co-design workshops, but it is not compulsory. These workshops will involve 10-15 people, including other individuals with MS, healthcare professionals (such as neurologists and MS nurses), and representatives from MS charities and minority health organizations (e.g., the South Asian Health Association).

During the workshops, the lead researcher, another researcher, and four co-researchers will guide the group in generating new ideas to enhance MS services and communication. Each workshop will last for two hours and will be tailored to accommodate the needs of people with MS. The session will be sound recorded.

If you prefer to communicate in a language other than English, we can arrange for a translator to be present during the interviews, focus groups, and co-design workshops.

Why am I being invited?
You are being invited to participate in this research study because:

- You are over the age of 18
- You are living with MS
- You have self-declared as British South Asian or Black British

You should not take part in this study if you:

- Are under the age of 18
- Are not living with MS
- Do not self-declare as British South Asian or Black British

Do I have to take part?
No. We have created this information sheet to help you decide if you want to participate in this study. It's entirely up to you to decide whether or not you want to participate. If you do choose to participate, you can withdraw from the study at any time, for any reason, without facing any consequences or negative effects.

What are the possible benefits of taking part?

By taking part in this research study, you may be able to use your personal experience to improve service access and information for the intended group of participants. This could be a potential benefit for you and others in the future.

What are the possible disadvantages and risks of taking part?
We don't expect to discuss any upsetting topics during the interview, focus groups, or co-design workshops. However, if anything comes up during the focus group that upsets you, please let the researchers know as soon as possible.

During this study, should information be disclosed which legally requires the researcher to breach confidentiality (e.g. safeguarding), they will report this information to the relevant authorities.

Expenses and payments
We will give you a £25 voucher for every hour that you spend participating in this study. If you attend any face-to-face sessions, we will also reimburse you for any travel expenses. Queen Mary University will either organise your travel or reimburse for these expenses once you have completed the session.

What information about me will you be collecting?
We will ask you questions during the interviews and focus groups around your thoughts and experiences of receiving MS care.

How will we use information about you?

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. All sound recordings will be transcribed by the qualitative researcher. This is when it will be anonymised. Direct quotes may be used in publications, but these will not hold any identifiable information. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

When and how will my data be destroyed?
Data will be securely stored in pseudonymized form in QMUL servers for 5 years in accordance with the data protection guidelines of the Queen Mary University of London. At this time, any paper records will be physically destroyed such that the information cannot be recovered and disposed of via confidential waste. Electronic folders and files containing electronic records (audio recordings, transcripts) will be deleted. The identifiable recording will be deleted 12 months after the end of the study.

What will happen if I want to withdraw from this study?
You can withdraw your participation from this study at any time without providing a reason. If you withdraw after participating in the interview, focus group or co-design workshops, you will still be paid compensation for your time.

Should you wish to stop taking part in the study your voice recording will still be retained. You will have up to the point of when the recordings are transcribed and pseudonymised to withdraw your information from the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/ by asking one of the research team, or by sending an email to [data-protection@qmul.ac.uk.

How will results of the study be shared with participants?

The researchers will return the key findings to the study participants along with a letter (sent via email) of thanks. This will also include a one-page hand out summarizing the key findings from the research.

What should I do if I have any concerns about this study?
If you have any concerns about the way the study was conducted, in the first instance, please contact the researcher(s) responsible for the study, Alison Thomson a.thomson@qmul.ac.uk. If you have a complaint which you feel you cannot discuss with the researchers then you should contact the NHS PALS service:

Who can I contact if I have any questions about this study?
Alison Thomson, lead researcher, a.thomson@qmul.ac.uk

Consent Form

Title of Research Study: Participatory Research into Minoritised Patient Experiences of MS Care

Chief Investigator: Dr Alison Thomson

IRAS: 327170

Participant Identification Number for this study:

Statement	Initials
1.I confirm that I have read the Participant Information Sheet dated 04/07/2023 version 3.0 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected	
3. I agree to participate in the interviews /focus groups /co-design workshops.	
4. I understand that data collected during the study, may be looked at by individuals from Queen Mary, University of London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access this data.	
5. I agree to the interview/focus groups/co-design workshops being audio recorded with still photographs (co-design workshops).	
6. I will require/ will not require a carer to attend the interview/focus group/co-design workshops with me (please delete as appropriate).	
7. I understand that everything said within the focus group and co-design workshops are confidential.	

_____	_____	_____
Participant name	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

Durham University

School of Applied Social Sciences

Shaped by the past, creating the future

Community-based Participatory Research: Ethical Challenges

Durham Community Research Team
Centre for Social Justice and Community Action, Durham University

SASS Research Briefing no. 9

Introduction

This research briefing is based on a participatory scoping study funded by the Arts and Humanities Research Council as part of the Connected Communities programme.

The study examined ethical issues in community-based participatory research (CBPR), based on a literature search and the deliberations of a co-inquiry action research group. The co-inquiry group comprised five community partners, five academics from Durham and Newcastle Universities and two staff from Beacon NE.

Rationale

CBPR is increasingly popular, with a growing literature written mostly from an academic perspective.

By 'community-based' we mean research that tackles issues relevant to people belonging to, or with interests in, a community of place, interest or identity (e.g. local residents, community activists, members of community groups, staff of NGOs or other service-providers). By 'participatory' we mean some degree of active involvement of a range of community stakeholders in research design, process and implementation (e.g. as research commissioners, advisory group members, co-researchers or peer researchers). In projects with 'deep participation', ownership lies with the community rather than outside researchers (see Box 1). Other terms such as 'community-based action research', 'participatory action research', 'co-inquiry' or 'co-production' are also sometimes used to refer to research that is community-based and participatory.

The popularity of CBPR stems partly from the fact that it is an approach that can be used to engage groups that are perceived as 'hard to access' by professional researchers (for example, minority ethnic and faith groups, indigenous communities, people with disabilities) and through this engagement more equitable and sustainable outcomes may be achieved for those groups/communities. There is also an ideological rationale for CBPR, often framed in terms of an explicit value position involving a commitment to sharing power with those usually the objects of research, and to working for progressive social change. In the UK, CBPR gained recent exposure through the Beacons for Public Engagement initiative in higher education (2008-2011) alongside a general growth of interest in community-university research engagement and research impact.

The main focus of this study is the nature and range of ethical issues in CBPR, taking a broad definition of 'ethics' as relating to matters of right and wrong conduct, good and bad qualities of character and responsibilities attached to relationships. The subject matter of ethics is often said to be human welfare, but the bigger picture includes the flourishing of the whole ecosystem. The aims of the study reported here were to:

1. Provide a critical overview of literature on participatory approaches to community-based research, with a particular focus on ethical issues, drawing on national and international experience.
2. Offer guidance and recommendations to the Connected Communities programme on tackling ethical challenges in CBPR.

The main focus of this study is the nature and range of ethical issues in CBPR, taking a broad definition of 'ethics' as relating to matters of right and wrong conduct, good and bad qualities of character and responsibilities attached to relationships.

Types of CBPR

The initial database searches generated articles in a variety of formats, the most common being case studies of particular research projects or interventions. CBPR is noticeably popular in health research in the USA. Not all articles were explicit about the degree to which the reported research was community-based and/or participatory. If we assess studies along a continuum of community participation (Box 1), the majority of research falls into the fourth category (controlled by professional researchers, with some degree of community participation). This is unsurprising, given the searches focussed more on academic articles than professional or 'grey' literature. However, it also reflects the way research sponsors allocate funding and the requirements of universities for publication. Many accounts of research that are framed in terms of co-production betray moderate degrees of professional researcher control. Some articles include community partners as co-authors, but very few are written from a community partner perspective.

Methodology

The study was undertaken during March-October 2011, comprising:

1. A literature search.
2. Three Review Team meetings.
3. Three Co-inquiry Action Research (CAR) group workshops.
4. Three consultations with International Advisors.

Box 1: Degrees of community participation in research

1. Community-controlled and managed research, no professional researchers involved.
2. Community-controlled with professional researchers working for the community.
3. Co-production – equal partnership between professional researchers and community members.
4. Controlled by professional researchers but with greater or lesser degrees of community partnership, e.g.

- Advisory group involved in design, dissemination.
- Trained community researchers undertake some/all of data gathering, analysis, writing.
- Professional researcher uses participatory methods (e.g. young people take photos).

CBPR and ethics

There are two main ways that issues of ethics in CBPR are framed in the literature:

1. **CBPR is often claimed to be inherently more 'ethical'** (meaning ethically good) than so-called 'traditional' research in which there is alleged to be a clearer distinction between researchers and researched. Examples are often given of scientific/health research that has harmed/ exploited vulnerable participants, including indigenous or ethnic communities or people with disabilities. While these assumptions can be questioned, especially when CBPR is academic-led, it is presented as an inherently ethical model in that it is:

   a) more ethically-aware because it takes greater account of issues of power, rights and responsibilities and the roles of all stakeholders.

   b) more egalitarian and democratic, based on respect for and partnership with community members.

2. **CBPR entails complex relationships of power and accountability** and hence raises distinctive ethical challenges relating to developing/maintaining partnerships, difficulties in maintaining anonymity and blurred boundaries between researcher and researched (e.g. community researchers researching their own communities). Some ethical issues identified in the literature and by the CAR group relate more to the research topic and/or group/neighbourhood that is the focus of the research (i.e. sensitive issues or disadvantaged groups) than specifically to the fact that the approach is CBPR. But it is hard to disentangle approach, methods and topics, as CBPR often focuses on disadvantaged groups/neighbourhoods and sensitive topics. It may also be undertaken by researchers who are politically committed and wish to use the results for campaigning.

Examples of ethical challenges in CBPR

The most common explicit coverage of ethics in the literature relates to the operation of Research Ethics Committees or Institutional Review Boards and issues of confidentiality, informed consent, representation, anonymity and ownership of data.

These issues are common to qualitative research, but take on specific dimensions in CBPR. Implicit ethical issues are often embedded in discussions of research methodology and process, even if not named as such, particularly in relation to power, partnership and participation. The deliberations of the CAR group complemented the findings from the literature review, building on many of the key issues, providing more nuanced understandings or alternative perspectives and raising new issues less prominent in the literature. A selection of the main ethical challenges covered in the literature and discussed in the CAR group is outlined below.

1. **Partnership, collaboration and power.** CBPR promises a move away from the 'outside expert' and tokenistic involvement, placing emphasis on negotiating and developing relationships in specific cultural, spatial, political, historical contexts. Dodson et al. (2007:822) warn that "researchers must grapple with power and vulnerability – both those of other people as well as their own". Many articles refer to work with a social justice focus, including ethical issues relating to 'race', ethnicity and cultural difference. However, it is important to recognise that all CBPR involves navigating social difference. A range of articles provide reflections on relationships between professional researchers and community partners, echoing the comments of Dodson et al. (2007:823) that 'collaboration and the conventions of research methodology are uneasy partners'. The time taken to build trusting relationships (Love, 2011) and the mis-match between academic calendars, funding timelines and community needs and expectations also create challenges. Several articles discuss the importance of ongoing dialogue in building relationships of trust, relieving group tensions and planning outcomes (Johnson et al, 2009; Love, 2011; Mohatt et al, 2004; Springgate et al, 2009). Experiences of participation may not be universal and those involved may experience moments of exclusion and inclusion (Ponic and Frisby, 2010). Direct personal accounts shared in the CAR group illuminated the importance of relationships based on mutual understanding and respect for difference, and how these can develop into effective partnerships that address the needs and interests of academics and community partners. The focus of CBPR on relationships also suggests

that theoretical approaches to ethics that emphasise responsibilities and relationships (ethics of care) might be helpful in providing alternative/complementary framings to rights-based approaches (ethics of justice) (Charles, 2011).

2. **Community rights, conflict and democratic representation.** Despite the plethora of ethical codes for research, most are concerned with the individual rights of human subjects. CBPR raises the challenge of extending rights to groups or communities (Quigley, 2006). This creates problems, including defining what counts as a 'community'; the potential for conflict between individual and group interests; how to modify informed consent to take account of group characteristics; and issues of who best represents a group or community (Wallwork, 2003). Further complexity is added if the topic is controversial and opinions are divided within a 'community'/group. Interesting examples include research on female genital cutting in the Somali community (Johnson et al., 2009) and attitudes of people with disabilities to physician-assisted suicide/death with dignity (Minkler et al., 2002). However, other articles demonstrate the unifying potential of research that identifies and examines a common issue or problem. For example, Horn et al. (2008) report how internal conflicts were avoided in Native American communities by ensuring diverse groups unified around a common theme, emphasising consensus-building rather than division and difference. Traditional conceptions of representation may be difficult to apply in some settings, such as multi-ethnic neighbourhoods or amongst stigmatised and marginalised groups, where there may be a lack of pre-existing structure for representation (Shagi et al, 2008). Furthermore, as the CAR group deliberations indicated, communities may have their own ethical codes/framings that differ from or conflict with those of external researchers (see Kindon and Latham, 2002; Sanderson and Kindon, 2004).

3. **Ownership and dissemination of data, findings and publications.** Group and/or community involvement as research partners adds complexity when considering ownership of data and results. According to Quigley (2006:142): 'The most problematic areas of research ethics in communities are about data control, confidentiality, interpretation of results, ownership, publication of results and dissemination procedures.'

   Many community research partners may not anticipate these issues and hence, in the view of the CAR group, it is particularly important to negotiate before research starts. To avoid the academic exploitation of community data, stigmatisation of communities and violation of privacy, some CBPR projects develop agreements relating to data ownership and publication (Quigley, 2006; Maddocks, 1992). Several articles highlight the difference between 'traditional' ways of disseminating research amongst professional peers and CBPR, involving dissemination to communities and wider publics (Love, 2011). Community members of the CAR group stressed the importance of using plain language in community dissemination.

4. **Anonymity, privacy and confidentiality.** These issues are common in all social research, but distinctive questions in CBPR include:

1) How can communal as well as individual consent be negotiated?

2) What rights should a community have to demand confidentiality in relation to certain types of information?

3) Can anonymity of participants in CBPR be secured, especially if community researchers are involved and there is wide dissemination within the community that is the focus of the research?

4) Is the preoccupation with anonymity always desirable, as community participants may wish the community and individuals to be given credit and/or to be named in order to publicise specific issues and improve longer-term outcomes?

   To tackle these questions, many CBPR projects establish community-based agreements to ensure participants understand the research, that there is an awareness and explanation of community risks and benefits and issues of anonymity, coercion and voluntariness are discussed (Quigley, 2006).

5. **Institutional ethical review processes.** The context-dependent nature of CBPR makes it difficult to fit within institutional review frameworks, which are generally not established with CBPR in mind (Flicker and Guta, 2008; Love, 2011). They tend to assume: a clear distinction between researchers and researched; a requirement for individual consent to participate; predictability of process and outcomes; and control by professional researchers. Malone et al. (2006: 1915) argue that the current culture of academia often protects institutional power at the expense of community empowerment. In judging the overall merit of research proposals, Fundación Sabiduría Indígena and Kothari (1997) argue that benefits for local people should be given as much weight as theoretical and methodological aspects. As interest grows in participatory approaches, Moore (2004:145) suggests universities need to adapt to alternative research methodologies. Academic CAR group members offered examples of difficulties in gaining institutional recognition and ethical approval. Effective partnership was regarded as vital in highlighting institutional constraints experienced by academics, generally invisible to community partners, and enabling their negotiation in ways that allow representation of diverse viewpoints and needs. The value of a set of ethical principles for CBPR to be used in institutional ethical review processes was highlighted by the CAR group.

6. **Blurring the boundaries between researcher and researched, academic and activist.** CBPR often makes high demands on emotional and intellectual energy and may disrupt participants' personal lives (Moore, 2004). Tensions may emerge between the roles of academic and activist (Cancian, 1993); outcomes may be unexpected and painful (Miller, 1994). Transformation is often both an aim and outcome of CBPR - personal transformation as well as transforming social structures (Maguire, 1993; Carson and Sumara, 1997). Moore (2004:155) warns that 'transformation can be a difficult pathway filled with anxiety, self-critique and heightened awareness', so supportive institutional structures are required. CAR group members emphasised that community researchers interviewing or conducting focus groups in their own communities, or social welfare or health practitioners adopting a research role, need high degrees of self-awareness to ensure that privacy and confidentiality are not breached and professional and personal issues do not become damagingly blurred.

Recommendations for future research

1. Adoption and promotion of a set of ethical principles and guidelines for CBPR in the UK by researchers, research councils, research charities, universities and other research funders and commissioners.
2. Ethnographic research on the process of CBPR to provide detailed and nuanced accounts of ethical challenges and how these are tackled.
3. A review specifically focussing on grey literature to source accounts of CBPR from community perspectives.
4. Longitudinal studies of communities engaged in CBPR to trace longer-term outcomes in relation to the research and examine approaches to evaluation.

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Report and appendices

For full report follow: www.durham.ac.uk/beacon/socialjustice/reserachprojects/cbpr

There is a series of appendices that give further details of aspects of this study. These can be downloaded from: www.durham.ac.uk/beacon/socialjustice/researchprojects/cbpr

Appendix 1: Project participants

Appendix 2: A note on outcomes of CBPR

Appendix 3: Details of the literature search

Appendix 4: Preliminary report on Co-inquiry Action Research group workshops

Appendix 5: Towards draft ethical principles for CBPR

Appendix 6: Bibliography

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Session 4: Introduction to Qualitative Data Analysis

SAMPLE TRANSCRIPT 1

How do co-located welfare advice services support general practice work?

INT: In your own experience how do welfare issues such as problems with benefits, debts and housing affect patients?

RES: Okay, so currently our surgery doesn't have a erm, err, a service within the practice so erm, so in this area. So I work in [place deleted] Surgery this one, and [surgery deleted]. In this area, so there's quite a high, there's a lot of social deprivation, lots of patients are in temporary accommodation. There are err lots of issues with the accommodation that patients are in and so a lot of consultations, even if it may not be the first thing that they present with is sort of there in the background. So erm, social issues in, you know, a large amount of patients come in with. A lot of times they come in and they ask for letters so erm, so whether it be, so even this morning I had a patient that wanted a letter erm in regards to issues she was having with the council. Erm, she'd had a rat infestation and then the rats had put excrement, and she needed some help with that. And so a lot of times it is, a lot come in and there'll be something in the background and so usually it'll be erm sort of those kind of issues and they err come in requesting help. So usually sort of letters, erm, or advice regarding erm things like benefits and financial advice. And so normally, it's difficult to really address that as well as all their other medical problems plus sometimes we're not the best ones to be fully equipped with what is available for them. So what I normally do is I, so we have the [name of support service] on [road deleted] erm that is open during the week. So usually I, so I speak to them and then I usually signpost them to go there to them. Or if they are older, so Age Concern, erm, and they do sort of drop in centres, drop in sort of erm clinics as well so the over 65s. So that's usually what I do if it's something I feel that I am not really addressing that well, erm yeah.

INT: Why do you think they come to you with these issues?

RES: Erm, I mean generally they are vulnerable in terms of erm, a lot of patients don't have a very good sort of social network. Lots of families, isolated so breakdown in terms of like erm the extended family. So where previously a lot of people you know, I mean maybe slightly higher erm, or more affluent area where fall on hard times, they've got other people that they can sort of lean on. Actually a lot of times it is erm, err, yes so either they'll come to the GP or the nurse or someone they trust. They feel like, and a lot of times they feel like actually there's a erm, an absolutely erm health impact in terms of erm what they're going through so they will make an association in their head maybe that actually it's something that erm, a doctor needs to be aware of. But saying that I do get some patients that'll say oh they've been to the housing erm team or they've

been to see their solicitor, erm, or they've been erm, I don't know to the Job Centre and the people there have said for them to come to the GP. So often things like letters, which is really unusual because erm there was a thing I think in [place deleted] a few years ago where they said that they didn't want doctors to do letters anymore for housing but I do get a lot of patients saying actually that places like Housing Authority and Job Centres actually do tell them to come back to see the GP to get things like letters. So sometimes they are actually advised to come to see us.

INT: Right.

RES: It's like the last point, they don't know what else to do and err, yeah, they come in.

INT: Yeah, and how do you think, if at all, do you think these issues do affect their health - do you think there is a link with health in any way?

RES: Yeah, I mean obviously sort of bio-psychosocially there is a link so you know if their living circumstances are poor, and they are worried and stressed about that, if they are having to live in a very cramped accommodation with lots of people, if they assess their psychological health, it's not their medical health. Erm medical health is difficult to know. I am not a housing expert. They will come in sometimes with photos of damp and err, and obviously there will be sort of a link to some respiratory conditions with that. Erm, but definitely psychologically there'll be issues there. So yes, I suppose so.

…….

INT: And how do you see your role as a GP, in terms of addressing you know the sort of underlying social issues?

RES: I suppose err it's not great. You often feel quite dissatisfied in what we can do socially because actually that is really a large thing that, that is basically the crux of a lot of patients, the reason why they come in. so we can fiddle around with medication, we can talk to them about medication or counselling and those kinds of issues but actually if the part of what's going on is that they are living in terrible accommodation, no matter amount of sorting that kind of stuff out is going to really help address it. Yeah, I suppose you feel, I mean I definitely feel erm in a way that the sort of, skirting over the issues. Because resources in terms of actually what we can do for housing or the social things are limited. Erm, err, so yes, and obviously I am not as well equipped in terms of, to give them that type of advice as maybe someone err, that sort of does this sort of daily or is involved in the housing team as well. Yeah, so dissatisfied really. Erm, but also there is, I mean there's a huge housing crisis in [place deleted] at the moment so patients are waiting for months. Erm, so I mean, yeah I mean definitely resources are strapped everywhere so social

funding is low. Yeah, it's a bit of, it's sort of like a bottleneck at the moment where a lot of patients at the moment are presenting with issues that are very much socially related. And yes, it is a growing trend.

INT: Right, and how much of this, you mentioned this is really common, is this something that takes up, you know, does it affect your workload?

RES: Err, so yeah, the majority, I mean if I look at my list this morning, erm, okay one, two, so one, two, three, four, five, six, seven, eight, nine, ten, eleven, twelve, thirteen, fourteen, fifteen patients, out of those there's three hade some social issues, three, four, five, six, seven, seven of my face to face and then three of my telephone consultations were sort of socially driven so that was the majority. Erm, I suppose it, it's time consuming. Probably not, time-consuming over a length of time because social issues things is never just one consultation, they will come, it'll be a patient that sort of chronically comes in to the background. So yes, this is time-consuming but I suppose that's not then major crux of it, it is the fact that actually sorting that, those kinds of issues out takes a lot of time and sometimes it is behind the case we can do in primary care really. But yes, obviously it means that a lot of appointment times goes on these kind of issues when you know, which may not be clinically driven but ...

INT: Okay, how do you think providing the [name of support service] service erm actually at the practice might influence that, if at all. Do you have any thoughts on that?

RES: I know when I do signpost people to go to [name of support service] and then I follow them up afterwards, they do end up going. The issue that they had sometimes been having is language. So there are a lot of patients here that don't speak, or English isn't their most comfortable language to speak so they have to sort of go and they find it a little bit difficult. Erm, also patients want a fairly quick fix and I often have to say to them that's not the case, even if they go to the [name of support service], a lot of it is doing the legwork themselves. Erm, I think yes it would be helpful, I mean so [surgery deleted] surgery, it is quite small so I don't know how it would be attached to this smaller surgery. Maybe one of the larger ones. Erm, and I think, I mean I think it's a good idea really. I mean especially when you sort of come in, they'll speak about the main issue and then at the end they might sort of say something about a social issue but you don't really have that much time to really address it. I try and go okay, these are avenues you can go to. If there's something you know that they can get too easy or quick within the vicinity of a practice, I can't see that, I mean I can only see that being a good thing really.

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INT: I mean can you, just thinking of some of your own patients, can you see that some patients that might go to the adviser rather than booking an appointment or do you think they would book an appointment anyway?

RES: No, I can see, I mean when you first asked the question that's what I was thinking, I was thinking would they still come in and see us? It's difficult, there are some that are sort of so entrenched that they have to see a GP or someone. I think it's going to take time for them to develop a relationship with someone and it does depend on who is, I mean who is staffing, who is going to be running this and if they feel that they can trust that person. I think part of it being in a GP surgery automatically they will see actually the system in place, somewhere they are going you know and they will have a sense that it is like a reputable place. But I suppose it does depend on who they see and what level of relationship they have with them. I see, I probably would think a fair few would probably go to them first and it may take some time for them to just end up going to them initially.

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SAMPLE TRANSCRIPT 2

How do co-located welfare advice services support general practice work?

INT: That's great, thank you very much. So I just wanted to start by asking you, in your own words, whether and how social welfare issues affect your patients?

RES: Yes, I think it's a significant amount of work in general practice. Certainly in terms of benefits, housing, all kinds of problems. I am trying to think of a percentage figure to give you but it is very hard. Some clinics who can be as much as 30-40% of the patients we see would be social welfare issues, perhaps less in emergency clinic but in a pre-booked clinic it is very, very significant, yes.

INT: And can you explain a bit more about that? Do you mean in terms of their health is related to those issues or that those issues are the reason that they have come in to see you?

RES: I think it's both. Erm, probably see more people who have come to us with agenda regarding social issues for example, if they want rehousing, they've been asked that a doctors' letter would be of assistance or if they want to appeal benefits decisions, they have been told doctors' letters would help them. Erm, and then there are also the social issues where people are suffering from stress from work or housing we see, so that comes in that way. So I would say it is both issues.

INT: Mmm, and so just a bit more about how the stress impacts those patients, can you tell me a bit more about your experiences of that?

RES: Well I think certainly stress is a major part of mental health problems. Either people with serious erm psychotic illnesses or less serious depressive type illnesses, stress is certainly a factor either in precipitating or prolonging the illness. Err stress at work, stress at home, stress of extended family can easily precipitate depression. And if the situation is not ameliorated, our job is much harder in a very busy setting. We can give people referrals for CBT [Cognitive Behavioural Therapy] or drug therapy but unless often we can deal with the underlying stress problems the patients don't get better.

INT: Mmm, how do you see your role erm as a GP in helping with those issues?

RES: Well we certainly seem to be the crossroads for people. Erm, we are still considered the point of reference of agencies, for example housing officers, benefits, they would see GP reports as very important. Erm, so a lot is coming through us. I think patients as well would see us as their first point of contact to access for example psychological therapy, psychiatric help. So we are still very much in the middle of many, many systems.

INT: Mmm, okay, and so if somebody erm sort of came to you and were particularly upset about you know perhaps their benefits or something like that, what would you do?

RES: Well we are exceptionally lucky here in that we have [name of support service] once a week from [place deleted]. So I'll often refer people to the [name of support service]. If they live in [place deleted] unfortunately we have to send them up, quite a long way away, to [place deleted]. So it is quite a journey. As for myself, I find it very hard to keep up with the extra legislation and the benefits. I try not to give too much advice because I am usually wrong, I am usually about six months out of data. Sick notes and appeals. I mean if someone wants a letter for an appeal I can do that, I am confident but if they actually want advice on benefits I can't give any advice really. I can't give any reasonable, with confidence. And as I said to have [name of support service] once a week is excellent. I mean this has been going on, we've been very lucky it has been about 20 years we've had workers coming here, if not longer. I think it started in a very small way, about 25 years ago. We had maybe once a month and now we've got weekly sessions from [place deleted]. That is of great benefit, yes, definitely.

INT: Can you tell me a bit about how that sort of is situated within the practice. How is that service integrated into the practice as a whole?

RES: Well it is like a clinic once a week, I think every Tuesday morning they get the whole morning, we give them a room and we book people in. they are always busy, there's always a demand and people are very satisfied with the service because they can actually have advice as opposed to us, I can only really signpost people, I can't actually offer any advice.

INT: In your opinion, is it able to sort of divert patients away from clinical appointments?

RES: Erm, I am not sure if one could say that. Erm, maybe it would, it reduces the referral to secondary care but I think they would have to start with the GPs in primary care. So I can't honestly say it reduces the appointments with us. I don't think it largely does. I mean maybe prevents some follow ups. If they are getting good advice they won't come back to us quite so often or if they come back and so it is a more focused report they ask for which they've been guided to but I don’t think it honestly affects the workload.

INT: Okay, and does the, does it have any other impact on the practice? So if there wasn't a [name of support service] here, can you tell me a bit about how that might influence the practice?

RES: Erm, well as I said we are split in that respect. We have the [place deleted] patients who we can't send for advice and

[place deleted] we can and there is a big difference because, because the service for the [place deleted] patients is situated on site, I think it is, people take it up more. [place deleted] people we say you've got to make an appointment, got to go up to [place deleted] make an appointment, I think it happens less. I think they aren't served as well as the [place deleted] patients here. So literally we see both sides of the coin.

INT: Okay, and are there any other benefits do you think of having that service actually in-house if you like?

RES: Well on occasions err we have kind of developed a relationship with the err [name of support service]. They have come to speak to our educational meetings once or twice a year to try and keep us up to date with the latest changes. There is educational value to us clinicians here, erm and also there is, it goes both ways. They can sometimes knock on our door and say we have got a person we are worried about, would you arrange to see them. So it is very useful to have them situated here, definitely.

INT: Okay, and do you think all the GPs are sort of aware of it and use it in the same way?

RES: Err, well yes, yes, very much so because all GPs have an induction period here and explain all the attached workers. I think all clinicians, nurses as well know about the service.

INT: Okay, and how is that maintained? Obviously within so many services going on at the practice, how do you sort of maintain that sort of awareness?

RES: Well weekly education meetings, and at least quarterly meetings where we discuss what services are going on. And such a well-used service, I think everyone knows about it.

INT: And so do patients only go via the GP or can they book appointments themselves?

RES: They could in theory book themselves, yes, there's no barrier. I would guess, I am only guessing here, most have seen a GP first.

INT: Right.

RES: Err, I mean if they have seen the [name of support service] previously, maybe a few years ago they would know to ask reception. But I would guess they mostly go via the GP here.

INT: Okay, erm so just to ask you another question, you mentioned a bit about this, about them knocking on your door and things. What interaction do you have with the advisers at the practice?

RES: Well as I said we do invite them to our educational meetings erm once or twice a year and you know, meet them in the coffee room quite informally, and have a chat with them.

Literally they work in the room just opposite here so I often see them on Tuesday mornings so often have a chat with them Tuesday informally about some things. So it really is quite a useful working relationship, yeah.

INT: And do you think you need that sort of relationship for the service to work or ...

RES: It's an added bonus put it that way. I mean I think it would work anyway. It just seems to work a little bit better if you've got some kind of human contact between us only, they are not working totally in isolation. I think it's the icing on the cake put it that way but the cake will still be there.

INT: Okay, and do you think that icing is sort of a benefit to the practice staff or to the patients or ...

RES: I think to everyone, erm, it keeps the practice staff more informed what's going on, the patients I think get a better service in that we, they know we are integrating better with the advice. So I think everyone is a winner.

INT: Okay, are there any other comments that you have about the [name of support service], erm, at all?

RES: Well I am just very, very positive because erm, you know health and social wellbeing, they are so interlinked. A) Because it's just the reality of the work and b) because erm people are coming via us to access social care and so we are very much involved. So it's been of great benefit to us. I mean I can remember when it started years ago, great to us, the patient, the practice, only got positive things to say.

INT: Okay, that's great, thank you very much.