Queen Mary University of London

MS Society

Session 3: Understanding Ethics in Research

Multiple Sclerosis (MS) Peer Research Study Research Training Programme (2024)

mspeerresearch.co.uk

Before we get started...

- Allow everyone to speak, one at a time.

- Respect everyone's comments and suggestions.
This is a safe space for everyone to share their ideas.

- There are no wrong answers. All comments and suggestions are welcome.

- Raise your hand to let us know you would like to speak or to ask any questions.

- If you need to take a break at any point let us know You do not need to state the reason.

- We will be **recording** the meeting to help us keep track of comments. We will only use the audio.

Welcome to Session 3 of MS Peer Researcher Training Programme!

Session Objectives

By the end of this session, you will be able to:

1. Get an overview of what ethics in research mean.
2. Understand the importance of ethics in research.
3. Learn how to make your research ethical.
4. Learn ways to protect your research participants

4 Discussion activity

What words do you think of when you hear the word ‘ethics’?

5 What are ethics in research?

- Ethics are the most important part of research.
- It relates to:
  - Doing good and harm.
  - The ways in which people are treated.
  - Acting with integrity as a researcher
  - Considering who gets to benefit from research.
  - The rights of research participants to information, privacy and anonymity.
- As a researcher, you must carry out research in the most ethical way possible otherwise, it becomes worthless and may even cause harm.

6 Key principles in ethics

Respect: autonomy, capacity & dignity

Doing good: wellbeing, minimise risk & protect

Justice: risk/benefit, equity & special protection of vulnerable groups

Versions of ethics in research

- **Ethics as regulation** – codes, research ethics committees (following rules: managerial ethics)

- **Ethics as decision-making** – dilemmas, difficult choices (making choices drawing on principles/rules: principle-based ethics)

- **Ethics as embedded in everyday practice** – ethics as embedded in the research process which includes our attitudes, ways of working, and relationships (e.g., being a certain kind of person) with participants.

Let's talk about key concepts in ethics

Term	Definition
Coercion	Unduly influencing someone's decision to take part based on an expectation of benefits or rewards, or because of a relationship or power dynamic between participant or researcher
Deception	Providing incomplete or false information to mislead participants (e.g., tricking them into participating)
Withdrawal	Participants have a right to withdraw from the research at any point, including the right to withdraw their data after they have taken part.

Let's talk about key concepts in ethics

Term	Definition
Anonymity and Confidentiality	participants have a right to remain anonymous (not personally identifiable) when sharing research findings, and confidentiality must be maintained. The only exception is it could result in harm for participants.
General Data Protection Regulation (GDPR)	a set of guidelines on collecting and using data in the European Union (this still applies to the UK). Anyone who works with data should undergo a separate GDPR training.
Data Protection Act 2018	The Data Protection Act controls how personal information can be used by organisations, businesses, or the government in the UK. You will need to undergo a separate data protection training before accessing any personal data.

10 What is informed consent?

Informed consent is a voluntary and freely given agreement to participate (take part) in research.

Research participants must have sufficient information and understanding so that they can make a meaningful decision about taking part.

Informed consent is not just a form that needs to be signed once – it is a process and participants can withdraw consent at any time.

Consent is one of the legal bases on which to process personal data under the General Data Protection Regulation ("GDPR").

Example of informed consent https://youtu.be/XucFuMYh0Mg

What is informed consent?

- Participant information sheets must be designed to help participants make informed decisions about taking part.
- Researchers must take the steps necessary to ensure that all participants in the research understand the process in which they are to be engaged
- The Consent Form concisely covers the main points of the Participant Information Sheet which is phrased as statements with which potential participants can agree or disagree.

Informed consent in our study

- Please note that you are not consentd to take part in our study because you are a member of the study team.
- You will not be taking consent from participants.
- Before the interview is arranged, Sharifa will contact the patient participants who were recruited through the clinical co-investigators to get their consent.

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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 _____

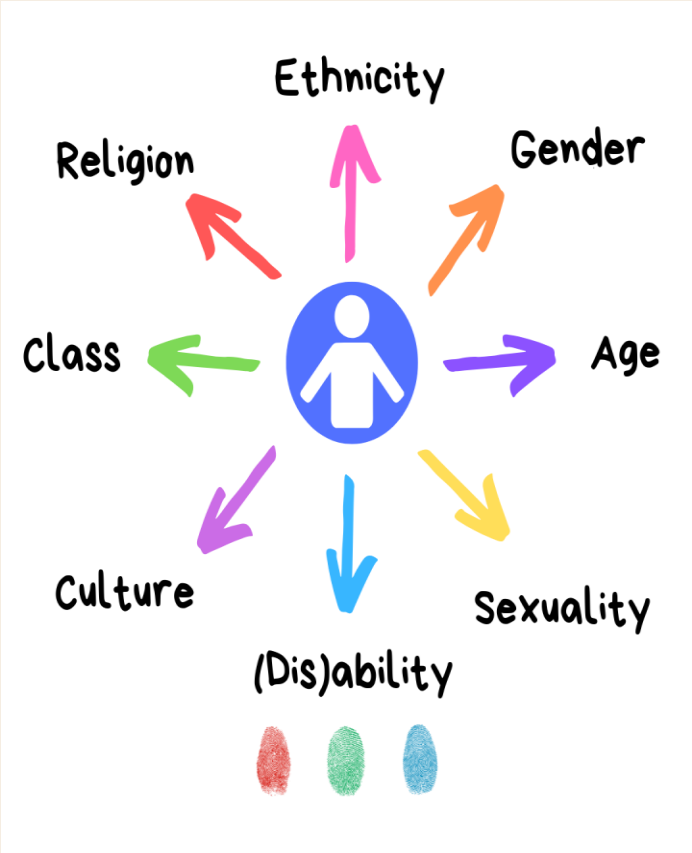
Power dynamics in research

- **Power** is the ability to direct or influence others. There are lots of different kinds of power, but you may often hear researchers talk about social or political power and power dynamics.
- **Power dynamics** refer to how different groups or individuals exert power over each other. Historically, some groups have held more power than others, and this power has enabled them to gain more resources than others.
- Peer research is about sharing power between researchers and peer researchers to amplify the voices of those from seldom-heard communities.
- Peer research can, to an extent, reduce marginalisation in research because it disrupts a traditional research dynamic, where a researcher distantly engages with a topic as an outsider.

Discussion activity

- Reflecting on the specialist MS care you receive:
  - -who has more power in the doctor-patient relationship?
  - -who has more power to decide on your care?
  - -what are the possible reasons for that?
  - -how does that make you feel?

15 Power dynamics in research

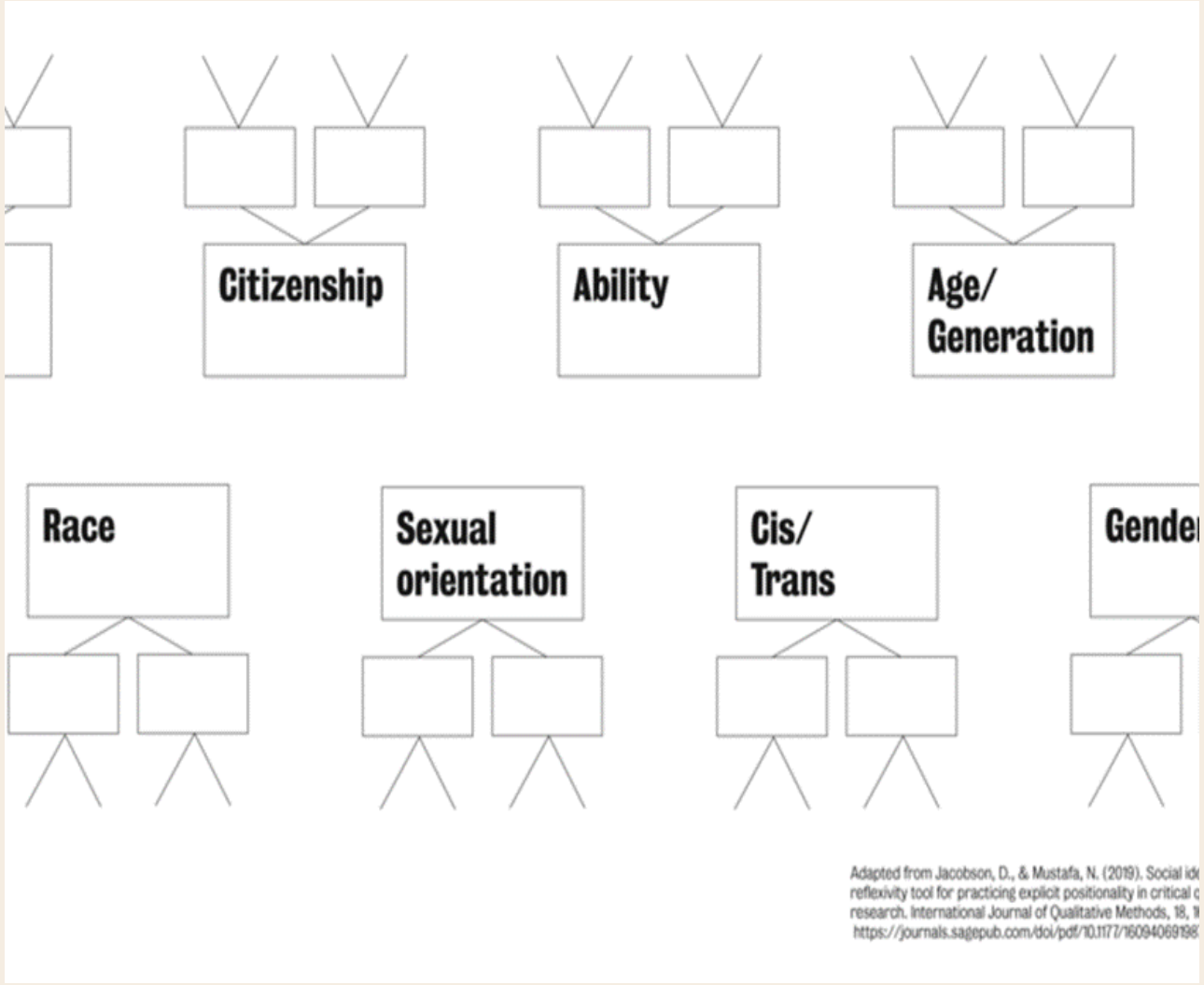


- **Power imbalances** mean that some individuals are members of more advantaged groups (e.g., White British men in living in the UK), whereas others are members of more disadvantaged groups (e.g., Black women who recently immigrated to the UK).
- Social groups/identities are interconnected, and how they can form different sources of vulnerability, discrimination, or oppression.
- One term used by researchers to account for power dynamics and imbalances that often accompany social groups/ identities is **intersectionality**.
- Overcoming the imbalance of power between researcher and research participant results in research that is truly grounded in lived experience and helps to fill the evidence gaps needed.


Break Time

17 Reflecting on our social groups and identities

- List some of your social identities/social groups, you belong to.
- Can you think of how each of your groups or identities may give you certain advantages (privileges) or disadvantages in relation to MS care?
- Who do you identify as a peer?



Safeguarding, risk and disclosure

- **Safeguarding** is about preventing harm, harassment, bullying, abuse, and neglect.
- Make sure that you are ready to respond appropriately if there is a problem. There may be situations where participants talk about a risk of harm to themselves or others.
- If you are conducting an interview face-to-face, make sure you inform Sharifa when you arrive at and leave the location.
- We will have debriefing sessions after the interviews to talk about some of the issues you encountered.

Discussion activity

Scenario 1

It's the day of your first interview. You start and have a good conversation with the participant. Towards the end, they share that they have felt suicidal and do not have any close friends or family to support them.

What would you do?

Scenario 2

A participant starts to ask you personal questions during the interview.

What would you do?

Discussion activity

Below are some common ethical challenges related to participatory research. Let's look at each one of them and discuss the questions:

- **Partnership, collaboration and power**: participatory research promises a move away from researchers being 'the outside experts' and places emphasis on developing relationships and collaboration with people with lived experiences. What are some issues that may arise in this process?

- **Demographic representation**: what is your opinion about using terms such as BAME to represent people from particular social groups in research? How do you feel about the term 'community'?

Discussion activity

- **Ownership and dissemination of findings and publications**: who 'owns' the research data? Who gets to decide where to publish the findings?

- **Anonymity, privacy and confidentiality**: what levels of confidentiality and anonymity would you demand in relation to some types of information?

Can you think of some ways to overcome these challenges?

Key points from Session 3

- **Ethics is the most important part of research.** Without it, research becomes worthless. Researchers are responsible for conducting research in the most ethical way possible.
- **Informed consent is necessary to make sure research is ethical.** This is usually in the form of an information sheet and a consent form. Consent can be given in written or verbal form, although there are circumstances where informed consent is not needed.
- **Peer research is about sharing power** between researchers and peer researchers to amplify the voices of those from seldom-heard communities.

23 Time for reflection

What went well?

What did you like?

What surprised you?

Did we achieve our objectives?

What could have been done better?

How will you apply today's learning?

How did the session meet your expectations?

What are you interested in exploring in more detail in the next session?

Next steps…

Our next and final training session will be on March 27th from (13:00-15:00). The session will be done face-to-face.

The session will cover qualitative data analysis.