

Session 1: Introduction to Peer Research

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

mspeerresearch.co.uk



2 Ice breaker activity: Let's get to know everyone



Please take turns to introduce yourself

Say something about yourself that many people do not know



Why are you interested in taking part in this study?
What skills do you aim to learn from this training course?



3 Meet the study team



Dr. Alison Thomson

Principal Investigator

Dr. Thomson is a designer and researcher based at QMUL. She is leading this study and managing its progress.



Prof. Ruth Dobson

Clinical Co-Investigator

Prof Dobson is a Consultant Neurologist at Barts NHS Trust and leads the Centre for Preventive Neurology at QMUL.



Prof. Helen Ford

Clinical Co-Investigator

Prof. Ford is a Consultant Neurologist at Leeds Teaching Hospitals NHS Trust and Professor of Neurology at the University of Leeds.



Prof. Eli Silber

Clinical Co-Investigator

Prof. Silber is a Consultant Neurologist playing a key role in involving participants from King's College Hospital.

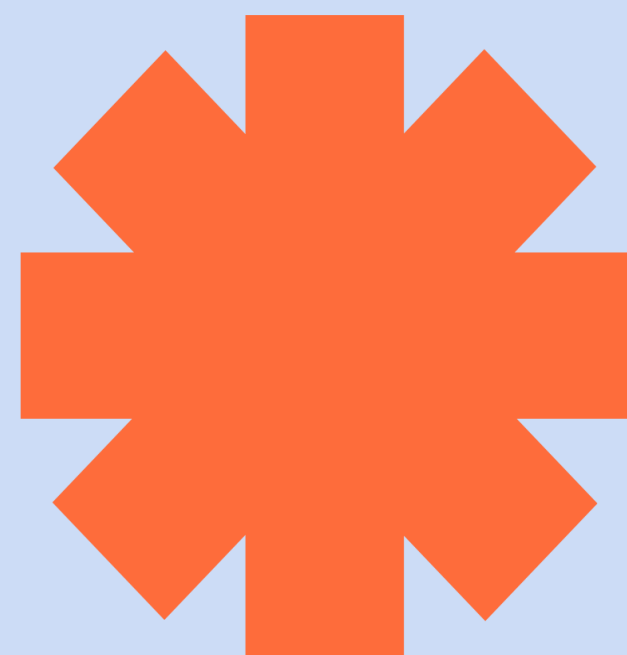
4 Meet the study team



Ms. Trishna Bharadia

**Patient Co-
Investigator**

Ms. Bharadia is an experienced and multi-award-winning patient engagement consultant and advocate, who also lives with multiple sclerosis (diagnosed in 2008).



Dr. Cord Spilker

**Clinical Co-
Investigator**

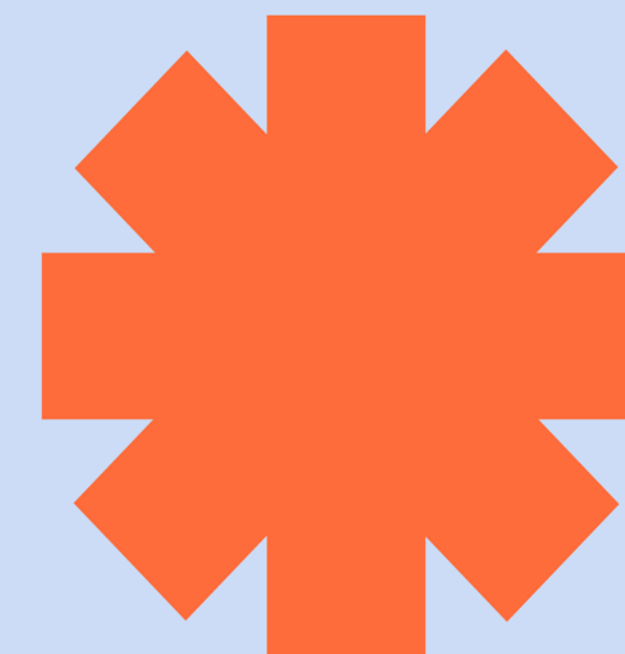
Dr. Spilker will invite participants from the Bradford Teaching Hospital area, building on his previous research with minority ethnic groups.



Prof. Carol Rivas

Research Consultant

Prof. Rivas is a professor of health and social care based at the UCL Social Science Research Institute. She has extensive expertise in participatory research with ethnic minorities,.



Dr. Sharifa Battashi

**Senior Research
Assistant**

Dr. Battashi is a qualitative researcher and will work with the study team to design and manage the progress of the study.

5 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 right or wrong answers. All comments and suggestions are welcome.
- Raise your hand to let us know you would like to speak, ask any questions or use the chat function to add any comments.
- If you need to take a break at any point let us know by using the chat. You do not need to state the reason.
- We will be **recording** the session to help us keep track of comments. We will only use the audio to refine the training program.

6 Your questions

Feel free to ask us any questions before we get started with the session. Your questions can be about anything, for example:

1. The research study
2. The study team
3. The peer researcher role
4. Practicalities of working together



7 Welcome to Session 1 of the MS Peer Researcher Training

Session Objectives

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

1. Get an overview of the research study, how you will be involved and how we will work together.
2. Understand the concepts of participatory and peer research and what they entail.
3. See how traditional research compares to peer research.
4. Understand why university researchers collaborate with peer researchers.



8 What is our study about?

- In MS research, people with MS from ethnic minorities are largely under-represented despite forming a large proportion of MS patients.
- Our participatory study aims to examine how Black British and South Asian people with Multiple Sclerosis (MS) living in London, Bradford, and Leeds experience MS healthcare.



**Multiple
Sclerosis
care**

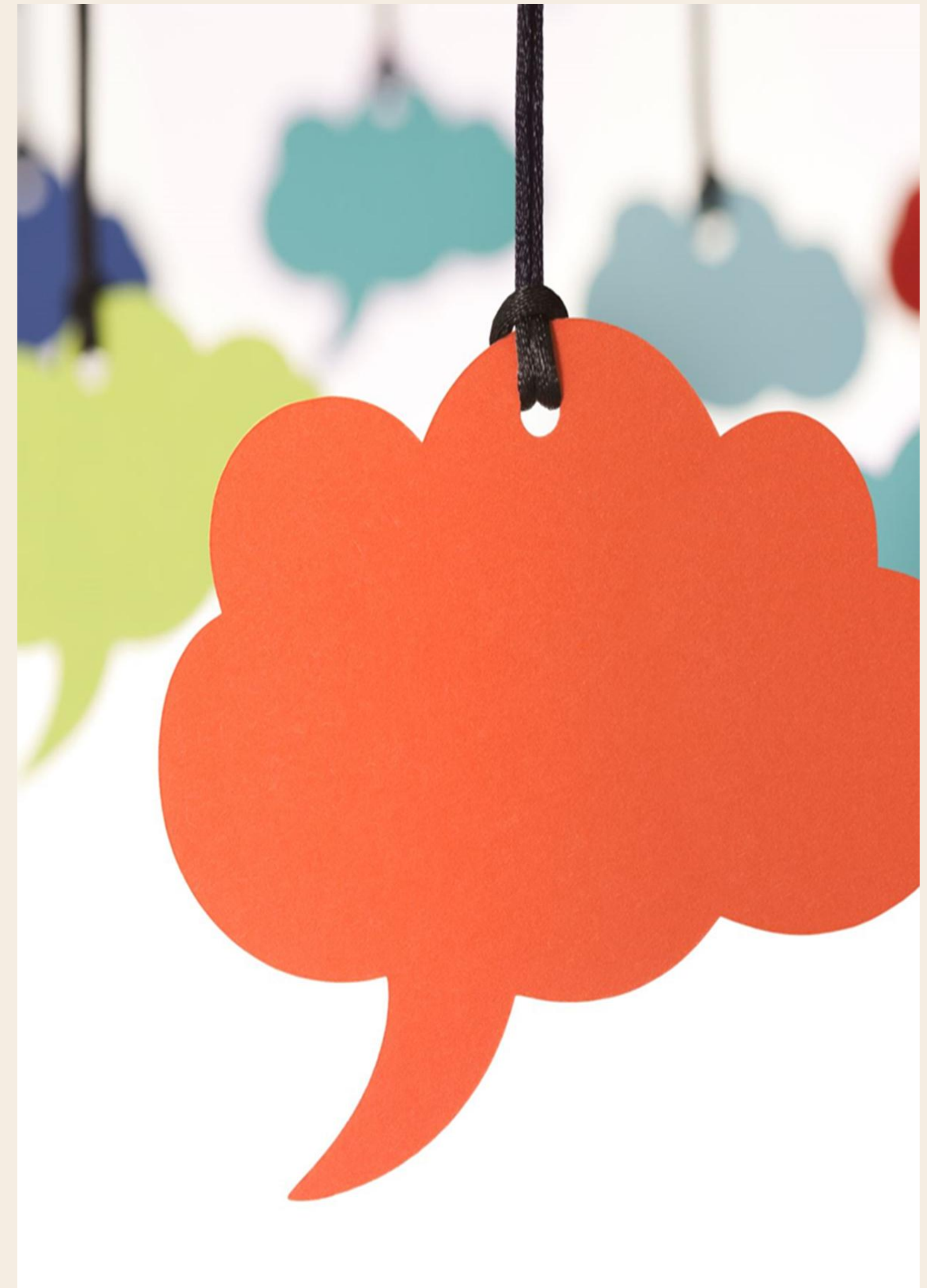
We plan to conduct this study by:

1. Getting people with MS from these ethnic backgrounds to speak to other people with MS using interviews and focus groups about their experiences of care.
2. Looking at interviews and focus groups to identify possible challenges and barriers to accessing healthcare services.
3. Designing solutions with healthcare professionals and other stakeholders to address issues.

9 Discussion Activity

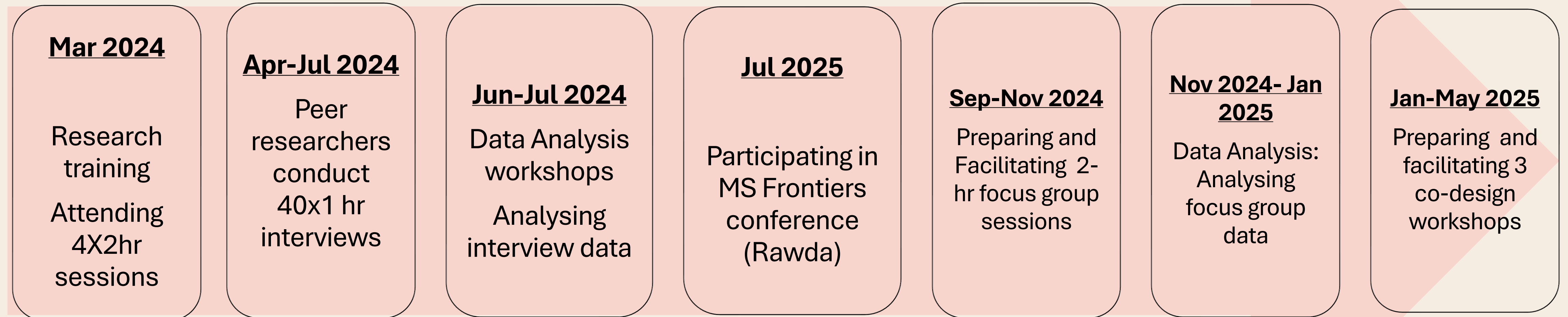
Let's talk about the following questions:

- Why do you think it is important to involve Black British and South Asian British people living with MS in our research study?
- What do you think it will help us achieve?



10 The MS Peer Research Study Timeline

We will work together in this study for 18 months



11 How we will work together



YOU WILL BE SUPPORTED BY US THROUGHOUT THE ENTIRE PROCESS

- You will choose your participation arrangements (Face-to-face or Online).
- Let us know if you have any accessibility requirements. Or if your circumstances change.
- Attend meetings with the study team.
- Draft interview and focus group questions
- Conduct interviews and focus groups.
- Analyse research data with the study team.
- Set priorities and help plan the activities for the co-design phase.

12 How we will work together

- You will be paid based on an agreed hourly rate (£40/hr).
- Payment will be calculated based on the activity done.
- In case of in-person meetings, we will arrange and pay for your travel. We will also reimburse any incurred expenses.
- The payment process will follow standard procedures used by Queen Mary University London. **You will need to complete and sign a BACS form with your bank details** which will be sent the relevant department at the university.
- Payments will be made directly to your bank account.

If you have any questions, feel free to ask or email us your query.

BACS form

To: Queen Mary University of London

FROM: _____
Name: _____
Address: _____
Postcode: _____
Email address: _____
Phone: _____

Date: _____

Dear Sir/madam,
Re: Payment for research volunteers, lay participants and volunteer participants in clinical trials

Please arrange for all future payments to me as part of my lay or volunteering role to be made directly to my bank account as per the following details:

Name of Bank: _____
Account Number: _____
Sort Code: _____
Account holder name: _____

I understand that it is my sole responsibility to inform HMRC and any benefit agencies of any money that I receive as part of my role as a research volunteer, lay or volunteer participant.

Kind regards,

Print name: _____
Signature: _____

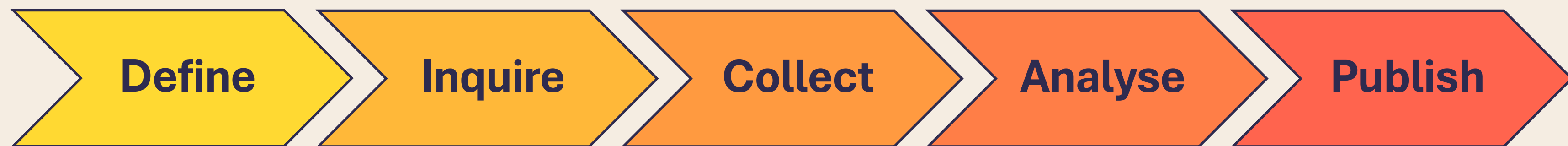


Break Time

13 What do we mean by 'research'?

- Traditional research is a **formalised process** of discovering and generating new knowledge about the world.
- Formal research answers research question(s) about topics of interest using specific rules and frameworks.

Traditional Research Process



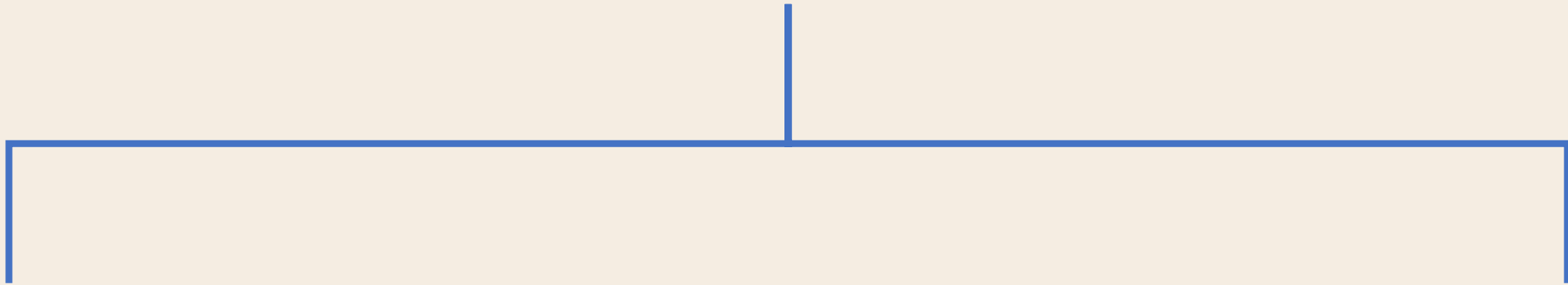
14 What is participatory research?

- PR is a **collaborative effort** in which people affected by the research **are partners** in all/parts of the process of designing, undertaking, and disseminating research.
- PR aims for social change using a democratic and empowering process.
- PR is often conducted using **peer research** where people concerned by the research with lived experience take part in directing and conducting research to generate information about their peers.



15 Participatory research has many approaches...

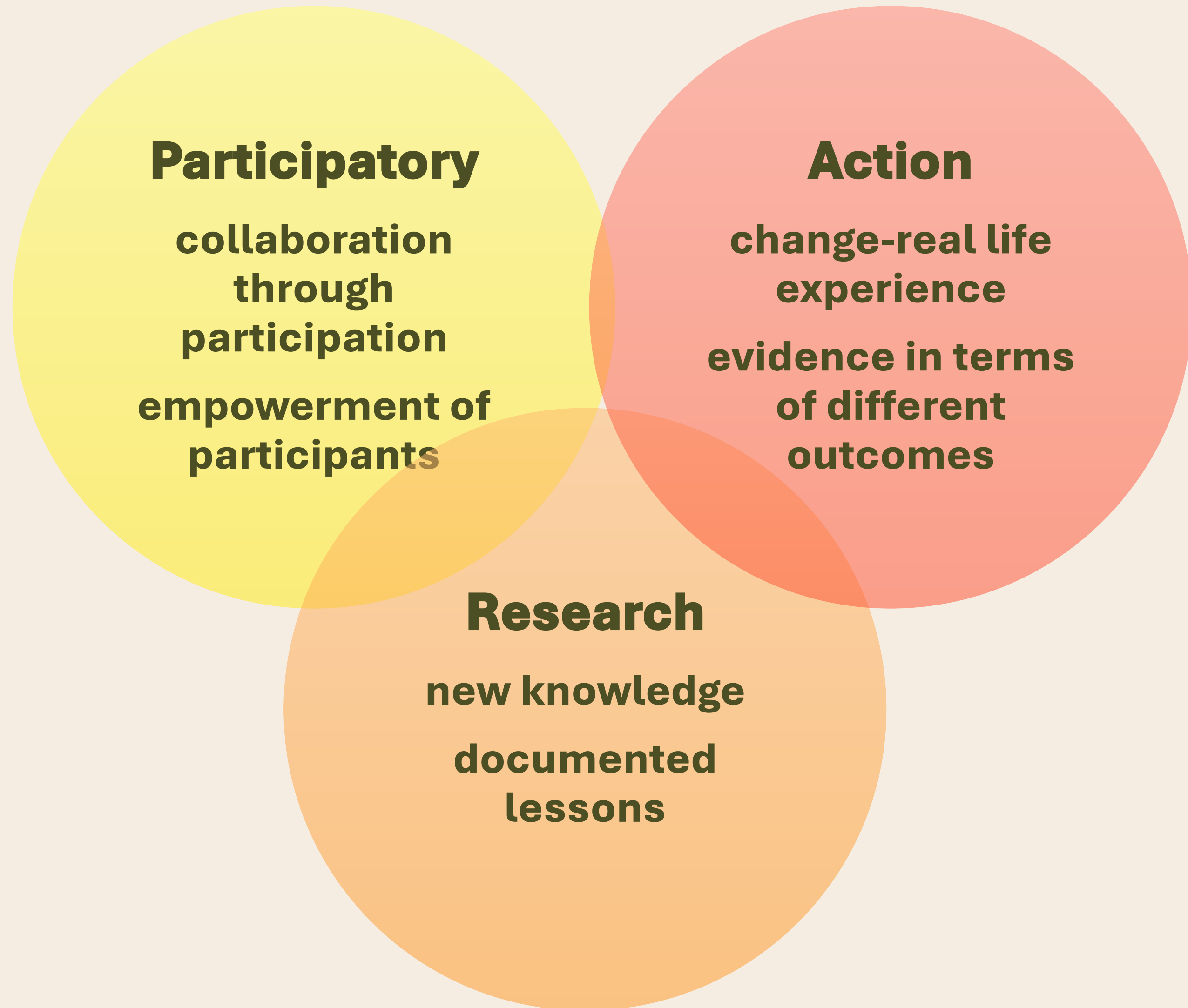
Participatory Research (PR)



- Patient & Public Involvement (PPI)
- Public Involvement
- Peer research**
- Collaborative research
- Stakeholder engagement
- Community-based participatory research

- Public Engagement
- Public Consultation
- Participative Engagement
- User- centered research
- Service-user engagement

16 What is participatory research?



17 Differences between traditional research and participatory research

	Traditional research	Participatory research
A Research aims and objectives	Issues identified based on existing data, research and funding opportunities	Peer researchers help identify relevant issues
B Study design	Based on scientific rigor and feasibility	Researchers work with peer researchers to design study to make sure it is acceptable
C Recruitment and retention	Based on scientific issues and “best guesses”	Researchers discuss with peer researchers how to recruit study participants
D Instrument design	Adopted/adapted from other studies; tested by the researchers	Adopted from other studies and tested/adapted to fit the people involved in research
E Intervention design	Designed based on academic literature and theory	Peer researchers involved in some/all aspects of development
F Analysis and interpretation	Researchers conduct analysis and interpret the findings	Peer researchers and researchers work collaboratively to interpret results
G Dissemination	Results published in peer-reviewed academic journals	Peer researchers assist researchers to identify appropriate venues to share findings; Results are also published in peer-reviewed journals

18 Why university researchers collaborate with peer researchers



1. University researchers don't know everything and lack detailed knowledge about people's experiences.



2. Peer researchers are experts in their own lives. They can help identify resources, challenges and research questions.



3. Amplifying the voices of groups that have been excluded from research in the past. This helps share power with peer researchers.

19 Who you are as a peer researcher

- You are “peers” to the research participants and have some shared aspects of personal experiences living with MS.
- Our research participants are people living with MS from South Asian, Black British or mixed ethnic backgrounds.
- You have a special perspective you can contribute to the research study.
- You do not need to have previous research knowledge, and you will receive relevant research training.



20 What do you want to gain from becoming a peer researcher?

Please choose an option or state any other reason(s) you find applicable to you.



Learn new skills and develop a career	Build your networks
Help address problems and create change	Try new experiences
Feel empowered	Gain opportunities and develop projects
Be a part of a team with like-minded people	Financial reimbursement
Improving a service/experience	Desire to make voice heard Being included in research

21 Key takeaways from today's session

Participatory research is a collaborative effort in which people are partners in all or parts of the process of designing, undertaking and disseminating research.

Peer researchers are individuals who receive training to take part in the research of a project, gaining many skills and benefits along the way.

Collaborating with universities has many benefits. These partnerships can be controlled by the community or the university, or co-managed equally.

22 Time for reflection



What went well?
What did you like?
What surprised you?
Did we achieve our objectives?



What could have been done better?
Do you need clarification on something?



How did the session meet your expectations?
What are you interested to explore in more detail in the next session?

23 Next plans

Our next session will be tomorrow on March 8 (13:00 to 15:00) online via Zoom.

The session will cover the basics of qualitative research methods (interviews and focus groups).

We will develop our interview questions in the next session

