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A project led by [Expert Focus](#) and the [NIHR Policy Research Unit in Health & Social Care Workforce](#) at King's College London, funded by the [UKRI Participatory Research Fund](#) and carried out as part of an [NIHR School for Social Care Research \(SSCR\)](#) study focussing on [strengthening Adult Safeguarding responses to homelessness and self-neglect](#)

Just another form of exclusion?

Carrying out research with people experiencing multiple exclusion homelessness
Key messages from a short film by Experts by Experience

Background to the film and report

In 2022 [Stan Burridge](#) at Expert Focus and [Jess Harris](#) at HSCWRU planned a participatory learning process as part of a larger study involving Experts by Experience (EBEs) and talking to people experiencing multiple exclusion homelessness (MEH).

This was an opportunity for people with lived experience to discuss being involved in research, why they might feel excluded and to offer researchers ideas to help them to be better included.

The participatory process developed into a short film which shares the discussion between EBEs. Participants brought insights from their own experiences, which include homelessness and street sleeping, NHS and local authority services, domestic violence, mental ill health, and drink and drug addiction.

Participants shaped the focus of their conversations, and individually agreed to be named, filmed and recorded, although other options were offered. They reviewed the draft film and this report, having editorial rights. They have reflected on both the process and the results:

'I learned a lot from listening to the others' input and views on the subject, and therefore I took a lot of positivity away.'

'Was great to be a part of it ... a lot of important points have been made.'

We want to promote research that is thoughtful and inclusive, and empowering to everyone who contributes to it.

Greta, Jo, Katy, Luku and Vincent have shared their discussion about research with people experiencing multiple exclusion homelessness in the accompanying short film and here – presented under six over-lapping themes and questions:

- ☞ **The importance of putting people at ease;**
- ☞ **Considering the presence or risk of trauma throughout the process, including follow up;**
- ☞ **Can we ask to hear people's stories without generating shame or 'misery porn'?**
- ☞ **Do we include people who are actively using substances?**
- ☞ **The value of lived experience beyond the interview: co-producing research;**
- ☞ **Feeding back the impact of the research: did it make a difference?**

Multiple Exclusion Homelessness: a definition

Multiple exclusion homelessness (MEH) is a term which captures the intersection of being homeless with other disadvantage and exclusion, such as trauma, mental ill health, poor physical health, drug and/or alcohol use, and experience of institutional care, criminal justice and other systems.

QUOTES FROM PARTICIPANTS

'I've done a few different research projects ... I've got complex PTSD; as I'm going down the long corridor not knowing where I was going made me nervous before I even got there ... I didn't know the person, I was nervous and there was a barrage of questions, and I've gone through lots of different experiences with Police, Social Workers, Court ... It affected my mental health for the rest of the week. So, I'm really mindful now when I do research ... that a lot of emotions might come up.'

October 2022

Editor: Jess Harris

Publisher: HSCWRU, London

Download this [report](#)

Watch the [film](#)

The importance of putting people at ease

Participants emphasised the importance of creating a process of involvement in research that would put at ease anyone who felt broadly excluded from social norms and spaces. An inclusive approach to taking part in a research interview includes flexibility over the location, setting and timings, and sensitive thinking about someone's comfort, including if they have eaten or would like a hot or cold drink. Participants considered approaches to encourage someone to have confidence to express themselves, the importance of the researcher being a sensitive listener and not 'pushing' too hard for answers: *'don't go at people like you're having a firing line'*. Relaxed and supportive body language is emphasised; folded arms or sitting formally behind a desk might exacerbate feelings of power and powerlessness within the room, and trigger sensitivity to feeling judged. However, *'keeping the boundaries'* remains important for the researcher, who should consider that they may be the only person who has offered time or demonstrated an interest in someone, so maintaining the distinction between the interview conversation and listening as a friend or counsellor is important, as is signposting that helps to connect that individual to support, rather than simply handing over service contact details.

Considering trauma throughout the process, including the follow up

Putting people at ease is necessary not just to encourage and enable individuals to participate in the research process, but as part of a wider understanding of the trauma that is prevalent amongst people experiencing, and with lived experience of, MEH. Researchers should be aware that re-visiting and sharing traumatic experiences can itself be traumatising: *'You're asking people to bare their soul'*. Kindness and empathy are important but participants cautioned that they can be experienced as being patronising or condescending, in inappropriate reactions, *'Oh my god, that really happened?'* The nervousness due to being interviewed, and a *'barrage of questions'* may be triggering of memories of interviews with the Police, social services, criminal justice system and other painful investigative processes. Emphasising early on and throughout the process that it is fine not to answer all questions, that it is ok to take a break at any time, and asking people prior to an interview if they have any sources of support if the interview is upsetting can help individuals to prepare and manage the process. If a participant feels exposed and vulnerable, from the sense that they have 'over-shared', having a clear process of support at the end of the interview and re-emphasising confidentiality may help. Individuals may be left feeling exploited if the value of what they have shared is not made clear, and the chance to reflect on the experience not offered. Following up, not just after the interview but in the next couple of days, is seen as good practice to ensure that anyone without support has not been left traumatised, and links with sources of support that were not taken up on the day may be welcomed at this point, *'Has it affected you in any way?'*

Can we ask to hear people's stories without generating shame or 'misery porn'?

A strong theme that was explored was whether individuals with experience of MEH will always need to tell, and re-tell their own personal stories in order to participate in research, or if there are other ways of being included in studies and contribute to shaping improvements in practice and policy. Can questions be asked that draw more broadly on someone's knowledge, opinions and expertise? Re-telling one's difficult journey can provoke intense feelings, such as shame, and has sometimes been characterised as a demand for 'misery porn' by well-intentioned researcher or service provider communities looking to paint vivid pictures of the system gaps and failures that individuals fall through.

PUTTING PEOPLE AT EASE

'People taking part in research, they need to feel comfortable ... let them choose a venue ... if they feel more comfortable sitting in a café or in a park then do that ... Before I've even arranged to go and meet someone, I've built up a little rapport with them over the phone ... you always make sure that they feel comfortable, as well as yourself.'

CONSIDERING TRAUMA

'I do understand the need for research because without research nothing's ever going to get better, but I think there's ways of doing it, make someone feel comfortable, make them feel valued, like they're important, what they have to say, their story, their experience is the most important thing in that moment, and not to minimise just because different people have different experiences, it could be just as traumatic.'

FOLLOWING UP

'You always make sure that that person taking part in the research is okay before they get into the building, they're okay while they're in the building and then they're okay when they leave ... not just the same day it's then next couple of days after, you have to make sure that they're okay.'

Do we include people who are actively using substances?

The inclusion of interview participants who are under the influence of drink or drugs was debated. An understandable starting point was avoiding including someone who was likely to be in a state of confusion or feeling frightened, but to let them know that you would like to include them at another time, when they are able to contribute. There was concern that individuals could be excluded by gatekeepers who might think that their views would not be sufficiently authentic or coherent because of some degree of substance use. Such approaches deny the voices and lived experience of important cohorts who are vital to inform research on MEH. Exclusion from research also contributes to the wider state of social exclusion that an individual is experiencing: *'I done a bit of research ... then got told that I couldn't speak to the other two because they'd had a joint ... I turned round and said 'I don't care' ... He burst into tears ... 'No-one ever wants to talk to me.'* It was agreed that basic ground rules for all participants are useful but those rules should apply whether or not someone is using substances.

The value of lived experience beyond the interview: co-producing research

The benefits of having Experts by Experience as part of the research interview process, helping interview guides to be relevant and understandable, and the research team to be relatable, developed into a discussion of broader co-production within research. Other noted benefits are the potential to model to the interview participant that an alternative reality can be attainable, and - for the lived experience researcher - the process of working positively in this field is a source of pride, and part of a strengthening sense of inclusion.

Feeding back the impact of the research: did it make a difference?

Research studies often offer feedback to participants, but this can be harder to guarantee without long-term email, postal or phone contact details for individuals. This is not an excuse for a research team to avoid investing time and energy in the feedback process, for example, texting people to let them know when research is published, presented, or has made an impact, and offering information. Our wider study made contact with interview participants experiencing MEH through day centres, advice services and specialist accommodation services that offer support, and these link organisations can be kept up to date so they can share the difference that individuals have made, in their contributions to research evidence.

FINAL WORDS FROM PARTICIPANTS

'I feel very privileged to take part in research, you can make better things for better people and I'm all for that, but it can be difficult, it takes time and effort, and it can be upsetting talking about your life experience, but I think it makes me a stronger person for it so I'm all for it.'

INCLUDING PEOPLE USING SUBSTANCES

'... at the end of the day they've still got a voice and it's still important ... you can tell if someone is totally like off ... If you don't feel safe that you can stop the meeting and say to them, 'We can't do this today, but we can do it another time.'

THE VALUE OF LIVED EXPERIENCE

'Whenever I go and I interview ... I turn round and tell them exactly who I am and that I know where they're coming from ... I have been in the place where they are, and I say to them 'it gets better if you want it to.'

FEEDING BACK

'Feedback is important, absolutely it's important ... to find out what the researcher got out of it, I think that's important, and of course I would be delighted to take part in research because if I can make a difference that helps just one person that's fantastic.'

For further information please contact Stan Burrige at Expert Focus: stan@expertfocus.co.uk or Jess Harris at HSCWRU, King's College London: jess.harris@kcl.ac.uk