

# The TIFFIN recommendations



## Involving people with lived experience of homelessness in palliative and end of life care research

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## Why is this important?

People experiencing homelessness (PEH) frequently face advanced ill health and death at a young age. The average age of death for PEH is 20 years younger than people in the most deprived 20% of the population.<sup>[1]</sup>

Despite the high level of need for palliative care within PEH, there is disparately low access to services.<sup>[2]</sup> People experiencing homelessness rarely have access to palliative care, meaning that their deaths are often unplanned and unsupported.<sup>[3]</sup>

**We want to try and make sure that everyone with palliative care needs is able to access the support they need. To do this, we need to work alongside people with different lived experiences to design services that can meet their needs.**

Co-research is defined as collaborative research 'with' the population of interest, as opposed to conducting research 'on' or 'about' them.<sup>[4]</sup> It aims to involve the people the research is intended to help throughout its entire process, from conceptualisation through to dissemination.<sup>[5]</sup> Co-research advocates listening to and involving the experiences and perspectives of people with lived experience (PWLE).

Within palliative and end of life care research, there has been increased advocacy for co-research and collaboration with those with lived experience of an illness, or their families and carers to identify and address research gaps.<sup>[6]</sup> There have been a number of successful examples of co-research, for example in developing culturally sensitive palliative

care interventions, bereavement drop in services, and paediatric palliative care. [7],[8]

However, to date, there has been very little involvement of PWLE of homelessness in palliative and end of life care research. A recent rapid review by our research team<sup>[9]</sup> illustrated that only three papers reflected on involving ‘inclusion health groups’ within PEOLC research. Of these three, only one discussed the involvement of PWLE of homelessness. ‘Inclusion health groups’ refers people who are socially excluded and typically experience multiple overlapping risk factors for poor health, which includes people experiencing homelessness.<sup>[10]</sup>

No papers reported best-practice guidance for co-producing PEOLC research with inclusion health groups. Thus, despite increasing focus on and advocacy for co-research in palliative care, there is currently no specific guidance for tailoring this involvement towards inclusion health groups, including people with lived experience of homelessness.

## **Aims of our work**

The aim of this study was to co-produce best practice guidance recommendations that can support researchers to involve PWLE of homelessness in their palliative and end of life care research. We aimed to develop these recommendations by working in collaboration with both PWLE of homelessness and professionals with experience of involving PWLE of homelessness in their research.

## **How did we produce these recommendations?**

Participants for this study were in two groups: PWLE of homelessness, and professionals who had experience involving PWLE of homelessness in their research. We carried out 16 interviews with professionals, and two focus groups with 11 PWLE of homelessness.

Within these, we asked people about their experiences of involvement in research, what worked well, and what they would change in future involvement. We collated this data into some initial key considerations and recommendations for involvement using reflexive thematic analysis.<sup>[11]</sup> We then adopted an iterative analysis process was then adopted, where we worked collaboratively with both professionals and PWLE of homelessness to gather feedback, and develop and refine the recommendations.

A detailed write-up of the methodology can be found in our two peer-reviewed papers associated with this study, found here: <https://link.springer.com/article/10.1186/s40900-024-00549-3>

# The TIFFIN recommendations



## T Transparency

- **Try to be transparent about the parameters of your research project.** What is a requirement (eg dictated by funders) and therefore cannot be challenged? Where do you have some flexibility?
- **Offer feedback to PWLE of homelessness after involvement.** What were the results of the study? What impact might this have? If possible, keep them involved throughout the entire process (eg, involve them in dissemination of the outputs).

## I Importance of engagement and rapport

- **Try to build trust and rapport.** Rapport should be genuine, not transactional. Researchers should expect nothing in return before the research has begun. For example, do activities together that have nothing to do with the research, eg going for a walk, doing activities, having a drink and cake.
- **Consider involving PWLE of homelessness that you have existing or previous links with as a form of community level peer engagement.** Researchers often see better responses from people experiencing homelessness when they speak with others who have similar lived experience. This could be through services that have existing links, third-party organisations or relationships with individuals. Be aware that 'lived experience of homelessness' has different meanings for different people.
- **Set clear boundaries for involvement.** Be clear about what PWLE of homelessness can expect from you, and what you want from them. It can also be important to hear what they would like to contribute or gain from the experience. For example, have an informal discussion, or anonymous survey at the start of involvement. One key boundary to set can be around confidentiality – where it is upheld and where it may need to be broken.
- **Go to people in the community.** Don't always expect them to come to visit.

## F Facilitating equitable involvement via person-centred approach

- **Go into co-research aware that it can be a messy process.** Prioritise safe, genuine and meaningful involvement that prioritises the person's wellbeing.
- **When doing research, try to make it easy for people to get involved. Be flexible.** Be prepared to throw away your meeting agenda if it helps. Start early. Don't rush. Have a plan B.

## F Financial recognition of people's involvement

- **Consider the best way to reimburse people in the context of their involvement.** What would people prefer? Can you offer flexibility for their preference within your institution? Will this impact people's benefits?

## I Involvement and growth: a trauma-informed approach

- **Be trauma-informed.** And be aware of its potential effects in your approach to involvement.
- **Ensure there is appropriate support for PWLE of homelessness.** This can include support on wellbeing and practical skills.
- **Offer training, coaching and mentoring.** Offering this to PWLE of homelessness can support the development of research skills.
- **Encourage reflexive practice for all.** Throughout involvement, ask: what was learned? What could have been better? This can be via a conversation or a written piece etc.
- **Offer support to staff.** This can be through frequent team debriefs and efforts to share the mental load.

## N Navigating institutional resistance and attitudes

- **Consider and plan for the time and effort needed to overcome or address institutional challenges.** Eg, payment methods and internal advocacy for involvement.
- **Evidence the value of involvement.** At the end of the project, demonstrate the value of involvement to counter some of the issues faced. Be clear about its impact.

# Key considerations

## Transparency

‘I think the minute that we shift from helping those people to sort of seeing ourselves intertwined in that, that’s the success. Like where it like moves out of that sort of, “Here let us do this for you.” And it’s you start to see how actually we’re all kind of linked here.’

– Research Assistant

In our interviews, many academic researchers thought that the ideal dynamic for involvement was to create powerless, hierarchy-free relationships between academic researchers and PWLE of homelessness. However, participants recognised that this can be difficult to achieve as many researchers are working from their homes or offices, and most have no experience of homelessness. Additionally, not all elements of the research are open to adjustment – some parameters are fixed by funding organisations.

If we cannot truly ‘share power’, aim to be transparent about what can or can’t be impacted by involvement. Honesty, respect and open communication are key to establishing a trusting working relationship.

## Importance of engagement and rapport

‘Engagement is over time. Like it’s not just like this one-off or this like here show up and do this. It’s can you demonstrate trustworthiness? If it’s done well and it’s done sustained, long-term relationship, relationally, I think it’s essential.’

– Academic Researcher

Engagement is a crucial first step in involving PWLE in research. Engagement

requires considerable time and effort, often with repeated attempts at and investment in building trust, at first expecting nothing in return. A big part of engagement is building rapport. It’s important to build trust to allow people to feel confident in sharing their experiences. It’s also important to set boundaries and manage expectations for involvement, to not over promise or inadvertently mislead.

‘She was doing some gardening with... them and that’s sort of totally irrelevant to what she’s doing but it’s getting them involved. It’s easing them in gently...Even like a biscuit doesn’t go a miss. You know, cup of coffee and a biscuit.’

– PWLE of homelessness

## Facilitating equitable involvement via person centred approach

‘The people that we’ve been involving certainly in the multiple exclusion homelessness studies they’re often not so far from very traumatic journey points in their life that they’ve escaped... So those ongoing relationships will still come up against people perhaps who have moved on from addiction, going back to addiction, have moved on from really extreme mental health crises, falling back into those crises, not, disappearing completely.’

– Academic Researcher

To ensure involvement is safe and meaningful, it’s important to recognise additional considerations for involving PWLE of homelessness without assuming or dramatising their needs.. Participants outlined how flexibility is critical to facilitating equitable opportunities for involvement and enabling person-centred involvement. This was described as challenging for ‘normal’ academic practice (i.e., how research

without involvement might typically be conducted), by introducing flexibility around as many aspects as possible. This included allowing extra time, removing strict agendas and considering accessibility requirements.

## Financial recognition of people's involvement

'There's like kind of rewarding you, kind of like valuing your time in a way, that you don't feel exploited in a way.'  
- PWLE of homelessness

The general consensus from professionals and PWLE of homelessness was to always offer recognition or reimbursement for time and effort spent in involvement. The best method of reimbursement was debated as between cash, vouchers and bank transfers. Particularly when considering PWLE of homelessness, there is concern that payments could affect individuals' benefits; it's crucial that involvement doesn't impact people's financial security. Many participants suggested, where possible, leaving the choice of reimbursement method down to the individual. Despite the method of reimbursement, PWLE of homelessness highlighted how impactful the payments were.

'So I got like a hundred quid, and it was the first time in [pause] oh, I don't know, I think I've been housed now for about five or six years, but it was the first time in that period that I actually had a fridge full of food and cupboard full of food and I wasn't just eating crap, because I actually had loads of food. So it helps dramatically, it does.' - PWLE of homelessness

## Involvement and growth: a trauma-informed approach

'Sometimes [involvement] makes you in pieces because you are going back to that time and it takes you backward to the timeline where you went - Your mind is saying, let's move on, that is the reality of life but sometimes when you put shoes in that time it breaks you. So aftercare is very, very important.'  
- PWLE of homelessness

Given the sensitivity and complexity of both homelessness and palliative care, it's essential to take a trauma-informed approach to involvement. PWLE of homelessness expressed the importance of having secure plans in place to deal with potential distress around a potentially emotionally charged topic and avoiding re-traumatisation. Where coaching, training and involvement are carefully considered, co-production of research may result in growth for both researchers and PWLE of homelessness.

For example, academic researchers said they learned different types of expertise, and gained a more realistic picture of people's experiences that helped them to develop as a result. For PWLE of homelessness, there is potential to create new experiences around the subject. PWLE can also benefit by growing their skills, confidence and self-esteem.

## **Navigating institutional resistance and attitudes**

‘All the systems and structures that we have that are really prohibitive around paying people, employing people, consulting with people, ethical approval, you really have to kind of rethink all of those and that’s a challenge.’

– Academic Researcher

Professional interview participants discussed the structural challenges related to carrying out involvement-led research within their institutions. Professionals felt that there was often stigma or assumptions around people experiencing homelessness, including being ‘too dangerous or too vulnerable’, or being unsafe to involve in research. Interviewees suggested that these structural challenges may exist, or be worsened, as a result of such stigma.

## **Conclusions**

This report outlines the TIFFIN recommendations and best practice guidance for involving PWLE of homelessness in palliative and end of life care research. The sixteen recommendations were developed collaboratively with experts in the field (both professionals and PWLE of homelessness), and are based on six key thematic considerations produced from the data. Keeping the best interests of the individual at the centre of our work, above and beyond following traditional research processes, is critical to promoting ethical, safe and considered involvement for this population.

Our TIFFIN best practice guidance and recommendations (TIFFIN; ref once in journal) can support researchers to co-produce palliative care research with people with lived experience of homelessness. As a population with high levels of premature morbidity, yet low access to palliative care, more work needs to be done to advocate for the involvement of PWLE of homelessness in PEoLC research, and to raise awareness of the TIFFIN best practice recommendations.

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