

## Tammy Prescott PPI Award 2025 runner up

<b>Project Title</b>
Exploring the idea of death cafés for people experiencing homelessness: a qualitative study
<b>Nominee(s)</b>
<p>I am nominating Jodie Crooks, from Marie Curie and Gareth Davis from Pathway.</p> <p>Jodie is the qualitative research manager at Marie Curie and Gareth took up the role of a co-researcher with lived experience of homelessness in a research project led by Jodie. Gareth is supported by the homelessness charity Pathway through their experts by experience programme.</p> <p>Gareth and Jodie collaborated to design, deliver and disseminate the small grant project. Gareth was involved in all stages of the research, from developing interview guides, co-interviewing participants, and undertaking thematic analysis. As some of these tasks were new to Gareth, Jodie developed introductory training sessions to support his learning throughout the project. I believe that the collaboration, and valuable contributions made by Gareth transformed this project into one that was rooted in real-world experiences, and more accurately reflects the nuance and complexity behind end of life care for people experiencing homelessness.</p>
<b>Short summary of the project.</b>
<p>People experiencing homelessness often die at a younger age than the general population. Terminal illness diagnosis often occurs late in its trajectory (if at all), leaving many people experiencing homelessness to die without adequate support from palliative care services. Despite the high rate of bereavement and exposure to death among people experiencing homelessness, there are rarely opportunities for them to reflect on their experiences, thoughts and preferences around death or receive bereavement support. Death cafés are a global social franchise, providing a space for people to participate in an open group discussion about death, dying and bereavement. They are free to attend and unstructured but facilitated.</p> <p>This project aimed to explore the idea of death cafés for people experiencing homelessness and raise awareness around the complexities and considerations for death cafés with this population. Jodie and Gareth undertook a qualitative study comprising of: interviews with nine professionals with experience of running death cafés for, or supporting people experiencing homelessness in other ways, and two focus groups with nine people with lived experience of homelessness. Reflexive thematic analysis was utilised to develop themes.</p> <p>Five themes were developed to highlight the perspectives and experiences of death cafés for people experiencing homelessness: Choice; Expertise in facilitation: recognizing risk and the unstructured nature; Promoting safety against potential risk; Potential benefits; and Potential practical considerations. Themes highlight the need for a trauma informed approach. Death cafés could be impactful, where done well, but they are not without risk.</p> <p>Death cafés for people experiencing homelessness pose risks that require comprehensive consideration and trauma-informed, expert facilitation. However, this research highlighted that a low-pressure space to explore thoughts around death, dying and bereavement is currently an unmet need within this population.</p>

## Patient and Public involvement in project summary

Gareth joined the project on a 0.1 FTE basis. He was involved for 4-hours a week across the 10-month project. Jodie and Gareth met at least weekly via MS Teams, Gareth also spent time working independently, as described below.

Jodie liaised with Pathway (a homelessness peer advocacy organisation supporting Gareth) prior to receiving funding, to ensure Gareth could be involved, and supported at the earliest possible stage, via the expert support provided by Pathway.

Together, Jodie and Gareth developed the research plan and application for ethical approval. Benefits of Gareth's input at this stage included ensuring methods, questions and prompts used in data collection were accessible and appropriate. Following ethical approvals, Gareth co-interviewed all participants alongside Jodie. He led a section of the interviews, and added his own prompts to the semi-structured interviewing. This had real benefits, as participants responded well to his involvement and he in turn offered his own relatable experiences and perspectives. This greatly enhanced the process. To ensure Gareth felt comfortable with interviewing, research process were adjusted to include a 15 minute preparation session with Jodie prior to each interview, and a 15 minute debrief afterwards. This provided space for Gareth to express any concerns about the interviews, and to reflect on the data collected. Gareth also attended and co-facilitated the focus groups with people with lived experience of homelessness. The impact here was clear; Gareth was immediately able to put participants at ease in the research setting. Gareth, Jodie and other members of the research team also completed reflective diaries to enable the experiences of involvement from different perspectives to be considered and learnt from.

Following data collection, Gareth supported data analysis. He undertook independent thematic analysis of interview transcripts, before discussing our codes and co-developing themes with the rest of the research team. Gareth's positionality of lived experience meant his contributions to the analysis provided perspectives rooted in real-world experience. For example, when discussing venues for death cafés, he explained his view that for many people experiencing homelessness, holding a death café event at a venue they already attend may make them feel pressured into attending, when they actually did not wish to discuss dying at that time.

Although Gareth had PPI experience, this project was his first experience of long-term weekly co-production involvement. Wherever there were tasks he had not previously experienced, Jodie supported him by sharing introductory training materials that they reviewed together to increase his confidence and learning. This is in line with the UK Standards for PPI (Support and Learning). For example, Jodie and Garth held a mock interview prior to data collection to encourage him to develop semi-structured interviewing skills, such as developing prompts in the moment and being confident bringing a participant back to the topic if they have veered. Jodie provided further support around thematic analysis. Here, to enable accessible co-production, it was important that we amended our research process. Gareth expressed he was not comfortable using NVivo software. Therefore, to ensure that he could contribute to the analysis, we provided access to office software and supported him with basic skills so he could engage in the research project and highlight codes independently.

Gareth also co-designed a poster which was presented at the Public Health Palliative Care conference in Bern, October 2024. Across a series of calls, Gareth's input to both the content and visual design of the poster transformed it to be more accessible (i.e., through colour choice), and context sensitive (i.e., through selection of appropriate images representing homelessness, that did not carry negative connotations). We also presented this work at Faculty for Inclu.

**Who is the project lead?**

Jodie Crooks, Qualitative research manager, Marie Curie

**Who was the funder for this project?**

Marie Curie  
Small grant scheme, grant ID MCSGS\_23\_01

**Are there any links or resources you want to share to support your nomination?**

Prior to this project, Jodie worked as the research associate on a piece of research led by Briony Hudson to develop recommendations for the involvement of people with lived experience of homelessness. Attached is a lay report from that project, and a peer reviewed article describing the TIFFIN recommendations. Jodie led the development of these recommendations which aim to support researchers to co-produce palliative and end of life care research with people with lived experience of homelessness. These recommendations formed the basis on which the current co-production outlined in this award was built, and ensured our practice remained safe, meaningful and prioritised the lived experience co-researchers wellbeing throughout.

Journal article: <https://journals.sagepub.com/doi/pdf/10.1177/02692163241259667>

Lay report:

<https://www.mariecurie.org.uk/globalassets/media/documents/research/publications/homelessness-and-palliative-care/j425-homelessness-best-practice-guidance-v5.pdf>