

A spotlight on: Involving people with Lived Experience Session links

Thursday 8 February 15:00-16:00



People affected by death, dying or bereavement offer valuable knowledge and expertise based on their lived experience. In this session we will hear from both researchers and people with lived experience. We will hear about recommendations for involving people with lived experience, including those with experience of homelessness.

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Introduction and welcome

Dr Briony Hudson (Marie Curie)

The TIFFIN recommendations for coproducing palliative and end of life care research with individuals with lived experience of homelessness

Jodie Crooks (Marie Curie)

The need for disease-specific end-of-life care approaches for terminal brain tumours

Dr Florian Boele (University of Leeds) and Peter Buckle (Patient and Public Involvement Representative)

We MUST be involved! 4 people with learning disabilities explain how they can be involved in end of life research – and why this matters

Film by Richard Keagan-Bull, Leon Jordan, Amanda Cresswell, David Jeffrey and Irene Tuffrey-Wijne (Kingston University)



Marie Curie links

You can find information for healthcare professionals on caring for people experiencing homelessness in palliative care:

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/homeless-people>

Marie Curie Bereavement support services:

<https://www.mariecurie.org.uk/help/support/bereavement>

Find out how we involve people with lived experience in our research through our Research Voices Group:

<https://www.mariecurie.org.uk/research/strategy/research-voices-group>

The TIFFIN recommendations for coproducing palliative and end of life care research with individuals with lived experience of homelessness

Jodie Crooks (Marie Curie)

Read the full article: Involving people with lived experience of homelessness in palliative and end of life care research: key considerations from experts in the field:

<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-024-00549-3>

Link to join the Marie Curie Project ECHO Homelessness network:

<https://www.mariecurie.org.uk/professionals/project-echo/homelessness-network>

Take home messages

- Co-production of palliative care research with PWLE homelessness is currently **scarcely done**, and an area that until this work, had no real guidance or recommendations to support it.
- Co-production will take **time, effort and resource**.
- However, this investment is crucial for facilitating **safe, meaningful involvement** that manifests **benefits for both the research and the person**.
- When co-production does occur, we need to **continue to evidence the impact** of this to enable it to become a more common practice.

The need for disease-specific end-of-life care approaches for terminal brain tumours

Dr Florian Boele (University of Leeds) and Peter Buckle (Patient and Public Involvement Representative)

Paper that Florian and Peter have published together:

<https://research.birmingham.ac.uk/en/publications/a-randomised-phase-ii-trial-of-temozolomide-with-or-without-canna>

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Information on The Victoria and Stuart Project:

<https://www.victoriaandstuart.com/>

Acknowledgements

Many thanks to the speakers for sharing their work at the Marie Curie Research Conference 2024.

If you have any questions, please contact the Research Team at Marie Curie:

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