

Reflections on co-producing palliative and end of life care research with co-researchers with lived experience of homelessness

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Why is this important?

- Co-production based research aims to recognise the unique expertise of people with lived experience (PWLE) and integrate this knowledge meaningfully within the research.
- Recently, there has been increased co-production of palliative and end of life care (peolc) research.
- However, PWLE homelessness are rarely included in co-production of peolc research.
- Given the disparately low rates of access to palliative care services against the high level of need in this population, PWLE homelessness are a critical group to engage in co-production of palliative care research.

AIM: To provide a multi-perspective reflection on co-producing palliative and end of life care research with co-researchers with lived experience of homelessness.

Methods

These reflections formed part of a larger study, exploring the idea of death cafés for people experiencing homelessness.

When developing the study, we worked with a partner organisation: Pathway – a UK-leading peer support charity for people with lived experience of homelessness.

Through this connection, we recruited a lived experience co-researcher. They were a member of the core research team, involved in:

- Co-developing study materials,
- Co-interviewing
- Attending / supporting focus groups
- Thematic data analysis
- Dissemination of the findings

This occurred over a 10-month period, at 0.1 FTE per week.

To develop these reflections, members of the research team maintained a reflective diary throughout the project.

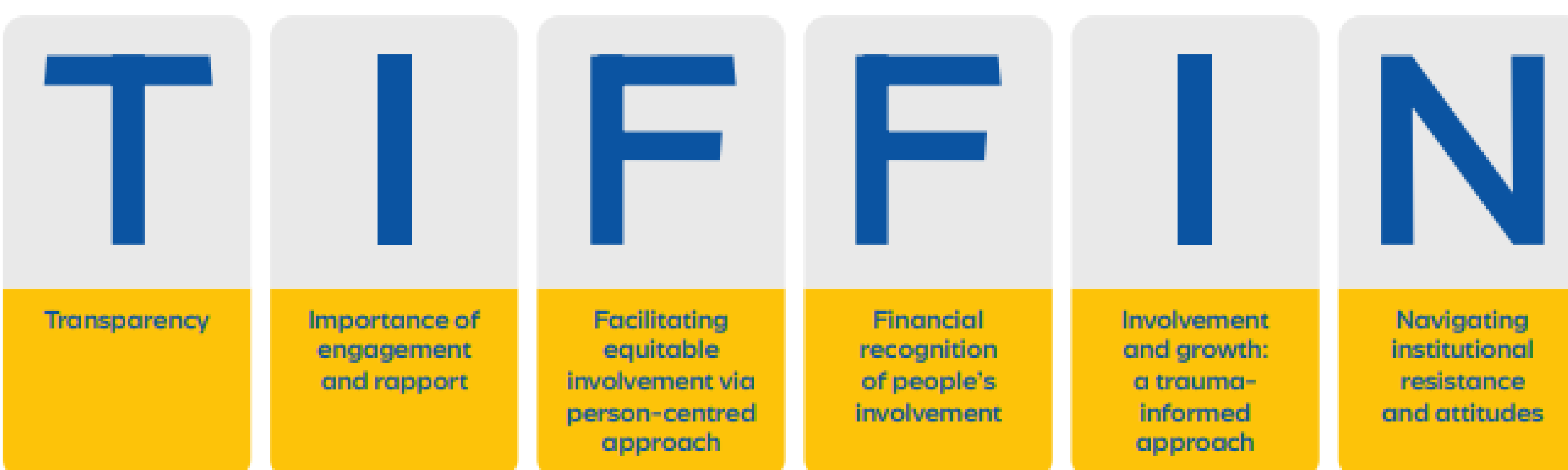
Conclusions

- Though it is not without challenge, working in partnership with a lived experience co-researcher has enhanced the depth, applicability and validity of our research.
- Partnerships with a third-party organisation can support processes such as payment and wellbeing support.
- These relationships, with organisations and people within them, are integral to a successful project.

TIFFIN Recommendations

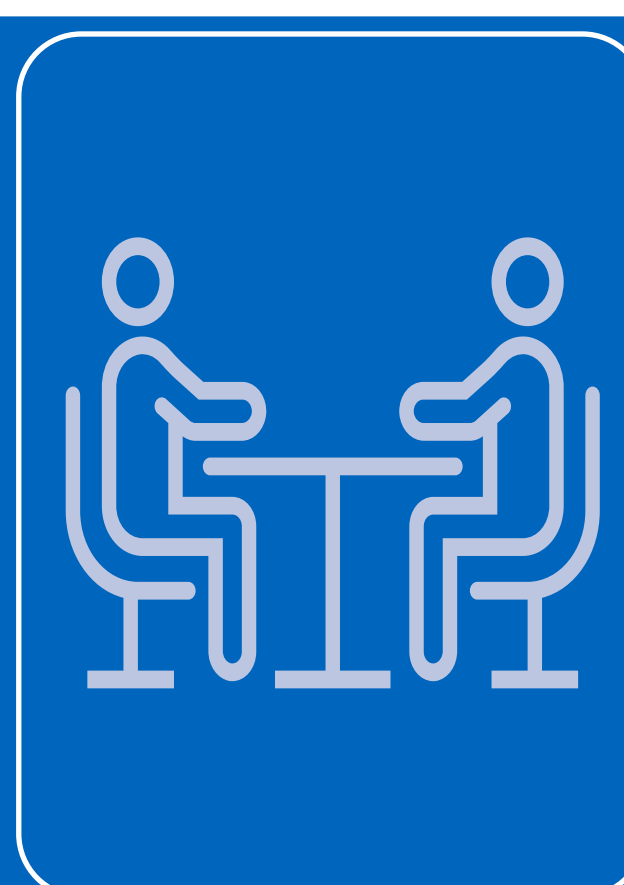
In previous work, some of the authors developed the TIFFIN recommendations: guidance on involving people with lived experience of homelessness in palliative care research.

Scan the QR code to access the full paper on the recommendations:



REFLECTIONS & LEARNINGS

NB. These are initial, high level reflections - not in their final format. We are working on a formal journal publication to provide the nuance to the work.



Working with partner organisation

- This has been integral to the success of the project.
- I acknowledge that we utilised an existing partnership, that has been cultivated over many years of collaboration and relationship building.
- The partner organisation has provided: emotional and wellbeing support for the co-researcher, payment processes / voucher distribution.



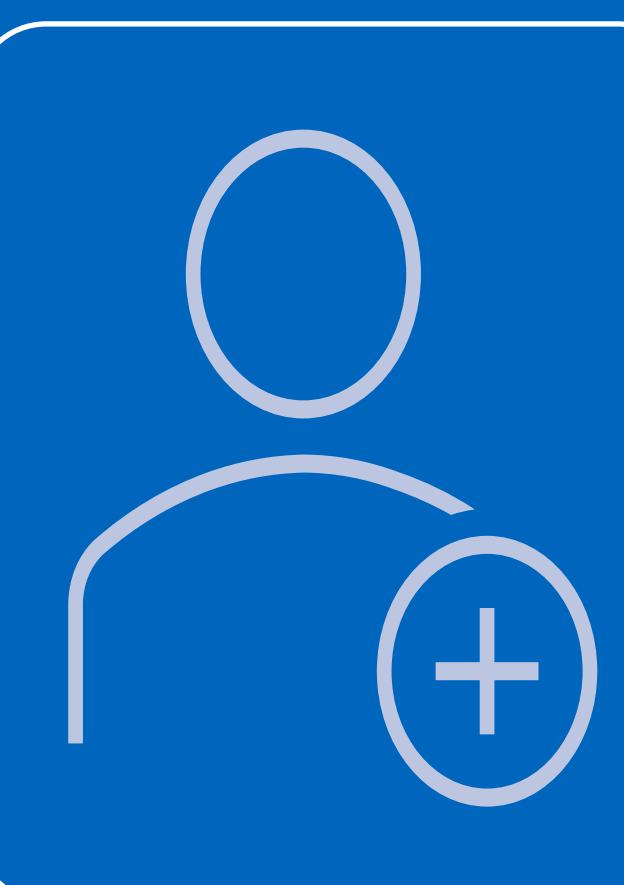
Flexibility

- Allowing cancelled meetings, planning (more than) enough time to reschedule
- Considering 'outside the box' approaches to research. E.g., does analysis need to be done in a software? Or can it be adapted to an accessible format?



Reimbursement

- Our TIFFIN recommendations advise to consider the best way to reimburse co-researchers in the context of involvement.
- Although we approached this hoping to work with Pathway to offer cash payments, our lived experience co-researcher expressed that they would prefer vouchers.
- This reflection led to us realising we had assumed about cash, when we should have outlined the options and encouraged choice.



Relationship building

- Building a trusting relationship with not only the co-researcher, but the third party organisation (if applicable) is KEY. You need to be able to ask them difficult questions, while understanding where everybody is coming from –this requires patience & trust.
- It is important to get a good understanding of a third party organizations' business as usual if you plan on working with them. Understanding if/what additional capacity you are asking them to take on.