

SWAT 236: IMPROVE: Intervention to optiMise Palliative caRe for peOple with liVed Experience of homelessness: reflecting on experiences of involvement in co-production of research

Objective of this SWAT

To explore the experiences of co-producing palliative and end-of-life care research with people with lived experience of homelessness.

Additional SWAT Details

Primary Study Area: Qualitative

Secondary Study Area: EDI; Incentives and engagement; PPI

Who does the SWAT intervention target: Patients; Researchers; people with lived experience of homelessness who are part of a lived experience group for a realist evaluation of an intervention

Estimated resources needed to conduct the SWAT: Low

Estimated cost of the SWAT (£): 10,000

Findings from Implementation of this SWAT

Reference(s) to publications of these findings:

Primary Outcome Findings:

Cost:

Background

Palliative and end-of-life care for people experiencing homelessness can be complex. This is due to many factors such as late or missed diagnoses and uncertain illness trajectories, substance misuse disorders, and an avoidance of discussing end of life. Therefore, co-production is key in working towards ensuring that research, services and policies represent this nuanced experience. Co-research draws directly from real world lived experiences through making people experiencing homelessness core members of the research team.

Despite evidence supporting the importance of co-production of palliative care and homelessness research, few examples of co-research exist in this field. Our rapid review found that although there are a few, good quality, qualitative studies offering insight into challenges and facilitators for lived experience co-researcher involvement, there was no best-practice guidance for co-production of palliative and end-of-life care research with inclusion health groups.[1] Therefore, we carried out a qualitative study to develop the TIFFIN recommendations: guidance for co-producing palliative and end-of-life care research with people experiencing homelessness.[2] These recommendations are currently being tested in an ongoing study and will be revised accordingly. The recommendations informed the development of this National Institute for Health and Care Research (NIHR) grant for the IMPROVE study, and will be assessed throughout this SWAT.

Host Trial Population: Adults

Host Trial Condition Area: Palliative care

Interventions and Comparators

Intervention 1: This will be a qualitative study using reflective practice via diaries and informal interviews. The use of a diary is a well-documented method for the provision of data in qualitative research.[3] It is a tool for prompting, capturing and exploring reflective thinking.

Participants in this SWAT will be members of the research team and lived experience group involved in the IMPROVE realist evaluation. A co-production group of six people with lived experience of homelessness will be recruited for the IMPROVE realist evaluation and all will be given the opportunity to be involved in the SWAT. In the first co-production group meeting (January 2025), the SWAT will be explained and members of the group will be asked if they are happy to participate. Some of the core research team (BH, SDS, CS) will also be invited to take part in the SWAT.

Method for Allocating to Intervention or Comparator: -

Outcome Measures

Primary Outcomes: This qualitative study will explore reflections on co-production of palliative care research from people with lived experience of homelessness.

Secondary Outcomes:

Analysis Plans

Data collection will occur in two main streams based on reflective practices; a methodology used by JC previously.[2]

Diaries: Participants will be asked to complete reflective diaries after each co-production group meeting. These meetings will be held every other month throughout the IMPROVE project, resulting in 18 meetings / diary entries. Prompts will be provided to guide reflections but participants can write about anything that is important to them. Suggested prompts will cover activities they have taken part in, what they enjoyed, what could have been better, and any other thoughts pertaining to that month's co-production.

Interviews: Towards the end of the project, all participants will be invited to do an informal reflective interview with JC. These will be semi-structured and aim to (a) clarify any uncertainties based on the diaries, and (b) expand upon key themes found in the diaries. Interviews will be held online, and last no longer than one hour.

Participants will write reflective diary entries in their own time following co-production group meetings. Reflective diaries will be stored on JC's secure UCL drive, in password protected Word documents. Interview recordings will be securely transferred to TP Transcription (UCL approved supplier). Transcripts will be anonymised, returned to JC, and stored on UCL's secure drive. Interview recordings will be deleted upon return of anonymised transcripts.

Informed consent will be gained from all participants via an online form, hosted in RedCap (UCL's approved software). This will cover issues such as using data from reflective diaries and interviews in reports and peer-reviewed papers and anonymity/pseudonymisation. Ethical approval will be sought alongside approval for the main IMPROVE study.

Interview data will be transcribed verbatim and anonymised. All collected data will be analysed through Reflexive Thematic Analysis.[4] After importing anonymised data into qualitative analysis software NVivo, the stages of reflexive thematic analysis will be followed: familiarisation with data, coding, generating themes, reviewing themes, defining themes and creating the report.

Possible Problems in Implementing This SWAT

Members of the research team and the lived experience group might not engage with the reflexive diary process.

References Cited in This Outline

1. Crooks J, Flemming K, Shulman C, Hudson B. Opportunities and challenges in involving people with lived experience of inclusion health as co-researchers in palliative and end of life research: a rapid review and thematic synthesis. *Research Involvement and Engagement* 2023;9(1):25.
2. Crooks J, Flemming K, Shulman C, Casey E, Hudson B. Development of the TIFFIN recommendations for co-producing palliative and end-of-life care research with individuals with lived experience of homelessness: A qualitative study. *Palliative Medicine* 2024;38(7):746-54.
3. Hewitt E. Building bridges: the use of reflective oral diaries as a qualitative research tool. *International Journal of Research & Method in Education* 2017;40(4):345-59.

4. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 2019;11(4):589-97.

References to This SWAT

none to date

Source of This SWAT

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Date of revisions: