

End of Life Population Board

Involvement Group Meeting

Thursday 9 March 2023 – 9:30am - 11am on Microsoft Teams (online)

Face-to-face meeting cancelled due to snow.

Note-taker: CB

Attendees: Chris Bridle - chair (CB), Kath Newton – ICB volunteer (KN), Julie Lawn - public (JL), John Curtain - public (JC), Kausar Iqbal - public (KI), Jenny Baines – EoL Board rep (JB), Jane Robinson – Leeds Bereavement Forum (JR), Claire Nixson – Forum Central (CN)

Apologies: Anne Heeson - public (AH), Liz Thompson - public (LT)

Agenda

1. Welcome and introductions
2. Notes of the last meeting
3. Draft terms of reference
4. Draft themes and actions document
5. Bereavement survey
6. Any other business

1. Welcome and introductions

The group introduced themselves and were welcomed to the session. CB summarised the discussion at the initial workshop and first involvement meeting. CB reminded people that more information about end of life work in Leeds is available on the Leeds Health and Care Partnership website here: <https://www.healthandcareleeds.org/have-your-say/shape-the-future/populations/end-of-life/>.

2. Notes of the last meeting

CB briefly outlined the notes from the last meeting. The group asked a number of questions and shared their thoughts.

- CB outlined that each board may have a different approach to involving people. For some boards this may involve having a public representative sitting on the board. The group discussed the pros and cons of this. CB explained that each board has representation from Healthwatch Leeds and the third sector. Agreed that a public representative on the board shouldn't be tokenistic and needs to be properly supported. This group will continue to discuss this.
- Group agreed that the insight report was useful and an important way to ensure that the voice of people from diverse backgrounds is heard at the board.
- The group asked for a diagram showing how various end of life and bereavement groups feed into the board.

3. Draft terms of reference

CB briefly outlined the draft terms of reference for the End of Life Involvement Group. The group discussed each of the six responsibilities of the group and generally agreed with all of these. The group shared some reflections on the draft terms of reference:

- Do we need to reference 'bereavement' more in the document?
- It was suggested that the board consider starting meetings with a short patient story. A number of these are available on the [Lippy People](#) website.
- Discussed whether the terms of reference should include what lays outside the remit of the group.
- The group were keen to receive a completed draft of this document so that they could look at it in more detail.
- It was suggested that the document should be written in plain English so that it is more accessible.

4. Draft themes and actions sheet

CB shared a draft themes and actions document. This document outlines the themes identified in the insight report and gives examples of what the board and wider partners are doing to address these themes.

- Discussed the difference between a 'theme' (several people experiencing something similar) and an 'individual experience' which is a one-off, isolated event. Agreed that individual experiences should be signposted to complaints and themes need to be added to the insight report.

5. Bereavement survey

CB briefly outlined the purpose and timeline for the Leeds annual bereavement survey. It was agreed that this group should receive a report from the survey and be involved in the development of future surveys.

6. Any other business and next steps

The group discussed the website and agreed that this was a useful place to signpost people but that it should mainly hold information about the board and involvement work.

The group identified a number of actions.

- **CB** to add meeting notes to the website
- **CB** to invite a board member to the next meeting
- **CB** to share a simple terms of reference for the group to consider
- **Members** to promote the work of the group in their personal networks
- **CB** to work with the board to complete the theme and actions document. This will be shared with the group
- **CB and JB** to update end of life structure chart and add to the website.
- **CB** to add 'bereavement' to terms of reference
- **JB** to discuss starting board meetings with a short patient story.
- **CB** to bring bereavement survey report to this group for discussion
- **Rachel** (Mooring) to set up a face-to-face meeting at The Old Fire Station in June 2023 (preferably on a Thursday morning).