

Life Stories Focus Groups

Topic guide

People with dementia

Before the focus group begins:

- Check that all participants have read and understood the information leaflet and would like to take part. Answer any questions and reiterate that involvement is optional, and that they can change their minds at any time.
- Have arrangements in place (family/staff member, interpreter, communication aids etc) to ensure that all participants can make an informed decision about taking part, and participate in the focus group fully, if at all possible. If a participant cannot make an informed decision about taking part, even with support, then they will be excluded. (Arrangements will have been made in advance to ensure there are staff on hand to support people who decide at this stage to opt out, or who do not have capacity on the day to consent).
- Support those who would like to take part to sign a consent form (this will include consenting to the focus group being audio-recorded)
- Participants were asked on the information leaflet to bring along a copy of their 'life story' or another object of significance to them – find out informally (for example, while supporting participants to sign consent forms) what participants have brought and whether they are happy to talk to the group about them – this information will help to plan and facilitate the discussion

Explain to the group:

- a) That the discussion should be grounded in mutual respect (everyone's view is valid, it is important to listen and not interrupt etc.) and that we are not looking for consensus - people can have very different views and this is fine
- b) That everything said in the focus groups should be kept confidential/not talked about in a way that makes other people identifiable outside the room (but they can talk to people about what they themselves said/felt – and Nada and Kate will be available after the session if they do want to talk about anything that came up in the discussion)
- c) The tape recording of the discussion will be stored securely at SPRU and participants' names will not be included in any reports that come from it
- d) Participants are free to withdraw from the focus group at any time – there is a separate room they can go to
- e) It is fine for participants to ask questions or take breaks during the focus group

Start

- START BY ASKING EACH PARTICIPANT TO INTRODUCE THEMSELVES (including how their dementia affects them day to day)

TOPIC 1 – How does it feel to tell your story?

- ASK THE PEOPLE WHO HAVE BROUGHT IN AN OBJECT OR LIFE STORY TO TELL US A LITTLE BIT ABOUT IT.

Questions:

- What have you brought in today?
- What is the story behind it?
- How does it feel to tell these stories? (probe for positives and negatives)
- Is it important to talk about these things/that other people know about them? Why/why not?

TOPIC 2 – Views on life story work

- SHOW EXAMPLES OF LIFE STORY BOOKS, BOXES, DIGITAL LIFE STORIES ETC (these will be mock-ups based on the Kate and Nada's lives)
- EXPLAIN HOW THEY CAN BE USED (in care settings, in the home etc)
- ANSWER ANY QUESTIONS PARTICIPANTS HAVE

Questions:

- What do they think of the life story books? (reasons)
- Why do they think someone might want to do a life story book/What might this achieve (and for who)?
- Why might someone not want to do one/what could go wrong?

TOPIC 3 - Good practice

Questions:

- **When** (and **where**) would it be good to make a life story book?
- **How** should the life story be recorded? (What tool? What sort of process? What should/shouldn't go in?)
- **Who** should be involved?
- How should the life story record be used **once it's made**? (Is it ever finished?)

TOPIC 4 - Messages for care staff/managers:

- What do they think care workers should know about doing life story work with people with dementia?
- What do they think managers/the people who plan services should know about this?

Anything else?

Finish

After the focus group has finished:

- Thank all participants for their contribution
- Explain the next stages of the project (transcription, analysis, checking back with the group re interpretation etc)
- Ask if the group (or any particular members) have any questions or concerns
- Hand out thank you letters and £10 gift.
- Stay long enough to answer any concerns people still have about the way the focus group went or any issues that were raised. Ensure that further support is available to anyone who requires this before leaving. Point out that the letter has a number people can ring if they want to talk about any of the issues raised today.