

Life Stories Focus Groups

Topic guide

Family carers of 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 remaining questions and reiterate that involvement is optional, and that they can change their minds at any time.
- Ask those who would like to take part to sign a consent form (this will include consenting to the focus group being audio-recorded)

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 Joy and Kate will be available after the session if they do want to talk about anything that came up in the discussion)
- c) The audio-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

Topics to cover

1. Experiences of life story work

What are their experiences of doing life story work?

Description:

- What did they/the person they care for do/make?
- When? Where? Who with?
- What happened (steps in the process)?
- How was it used after/is it used now?

Feelings:

- What was it like/how did it make them (the family carer) feel (during and after)?
- Positive bits? (probe for reasons)
- Negative bits? (probe for reasons)
- Could anything have made it better (ask for details)?

Outcomes:

- Has anything changed as a result?
- Do they think it has had an impact on anyone (professionals/carers working with them/the person with dementia/ family members/friends/other residents/themselves etc.)?

2. General views on life story work and good practice:

What do they think about life story work?

- Is it something people should do more of/less of (probe for reasons)?
- Are there any problems/challenges with it (ask for details)?

What is the best way to do life story work?

- How to record it (book, box, using a computer, collage etc)?
- Who with/when/where? (probe for reasons)

Potential outcomes/value of life story work:

- What could/should be achieved through life story work (how/why)?
- How should life stories be used?
- Who should use them/when/where?

Messages for care staff doing life story work and/or their 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?

3. Anything else

- Any concerns not covered
- Any constructive suggestions

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 £20 gift
- Stay long enough to answer any concerns people still have about the way the focus group went or any issues that were raised.