

Life Stories Focus Groups

Topic guide

Professionals

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 – 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. PERSONAL EXPERIENCE OF LIFE STORY WORK

What are their experiences of doing life story work?

Description:

- Where/what setting/when/Who with?
- Routine part of work or a one-off?
- Approach to recording the life story (what tool/type of record, who else was involved, what was the process)?
- How was/is the life story record used once made?

Outcomes:

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

Challenges of life story work:

- Have they ever had any problems doing life story work (probe for details, possible reasons and solutions/ways of avoiding such problems)

2. GENERAL VIEWS ON LIFE STORY WORK

What do they think about life story work?

- Is it something people should do more of/less of (probe for reasons)?
- What are/could be the outcomes of doing life story work?

What could be the problems/challenges with it?

- Description of problem?
- For who?
- Reasons for it being problematic?
- Possible solutions/ways of avoiding such problems?

3. GOOD PRACTICE

When/in what circumstances, would it be good to do life story work?

- Early or later in the dementia journey? (reasons)
- When someone uses a particular service/ moves into a particular setting? (reasons)
- Other times/circumstances?

How should the life story be recorded?

- What tool/format? (Book? Box? Collage? Computer? Other?)
- What sort of process? (One off? Over several sessions? On-going process?)
- How detailed should it be/what should go in?
- Who should be involved?

How should the life story book be used once it's made?

Are there any challenges to this (probe for details, possible reasons and solutions/ways of avoiding such problems)?

4. ORGANISATIONAL ISSUES AND COSTS

What would be necessary in order to make life story work a routine part of dementia care?

- What resources (including staff time, skills, equipment etc)?
- What training?
- Any changes to organisational culture/management approach?

Can you think of any other costs of life story work?

- To the organisation?
- To people with dementia?
- To families/friends?

How might the outcomes of life story work impact on costs?

- Changes to prescribing patterns?
- Changes to service use?
- Changes to demands upon staff?

5. SUMMARY

What is the best way of doing life story work with people with dementia?

What could help or hinder people to work in this way?

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