Appendix [posted as supplied by author]

Schedule used to interview researchers with experiences in end of life / palliative care research

Background Information

1. Current post?
2. Disciplinary background?
   - Any nursing / medical training / social work?
   - Did PhD / MSc / professional qualification involve end-of-life issues?
   - Where studied?
3. Can you tell me what your research interests have been?
   - Currently involved in interviewing / use of junior researchers etc?

Researcher's Experience

4. Thinking back over some of your research experience (link to previous discussion) – what do you think has worked well?
   - Example of particular study
   - Methods / approaches
   - Pro’s and cons
5. What about getting access to patients / carers – how did that go?
   - Ethics committees
   - Informed consent
   - Data protection
   - Tensions re writing / publishing / dissemination
   - Carer as protector / gatekeeper
   - Access to marginalised groups
   - Health professionals as gatekeepers
   - Poor health / fatigue etc as an issue

Research Methods

6. Thinking back over your research experience: what has end-of-life research meant to you on a personal level? (To get them to talk about rewards as well as challenges and coping strategies)

- Benefits / challenges
- Counselling / peer support / other coping strategies?
- Advice for new researchers?

7. **(For senior researchers)** Given the breadth of your research experience, you are probably in a good position to compare research across a number of areas. So, can you tell me – what, if anything, is different about doing / managing and supporting end-of-life research projects?

    - Training junior staff ?
    - Ongoing support?
    - Rewards / challenges

8. You were telling me earlier about the kinds of methods that work well for you - have you thought about (or used) any other kinds of research methods that might be considered out of the ordinary or innovative?

- E.g. use of film, video, audio, written diaries / narratives / creative writing / drama / art / music etc.
- Applying these?

9. Have you ever used a 'mainstream' method (such as face-to-face interviews or focus groups) but adapted it in some way to make it more appropriate?

- E.g. breaking off an interview and carrying it on later after the interviewee has had a rest; focus groups by audio-conferencing.

10. If you were conducting this interview, is there anything that we haven't covered that you would have asked about?

Focus Group Schedule

1. Introduction: the project & group

- Group
- Project

2. Have you ever taken part in research before? What was that like?

3. There are certain ways of doing research that are used often. How would you feel about taking part in the following …

(Each prompt to be prefaced by a short explanation.)

- One to one interview
- Paired interview (with another patient / carer)
- Focus group
- Questionnaire survey
- Participant Observation

4. Are there other ways that researchers could find out about your experiences? What do you feel about expressing your views through….

Keeping a daily / weekly / event diary (written, audio or video)

Creative writing (poetry, short stories)

Drama workshops

Art / Photography

5. Where would be the best place for a researcher to talk to you? What would be the most comfortable?

(To get at discussion about access; support etc)

- Home
- Hospice
- Other

6. Would you prefer to have someone else with you (carer / friend / family member etc) if a researcher wanted to talk to you about…

Your illness (experience of treatment stages etc)

Your experience of health services

Your emotional needs

7. Who would you feel comfortable talking to…

- About your experience of various treatments – that is, how you felt about it
    - Carer / family member / friend
    - Medical person
    - Another person affected by cancer
    - Researcher / stranger

- About your experience of getting access to services
    - Carer / family member / friend
    - Medical person
    - Another person affected by cancer
    - Researcher / stranger
- About your worries and emotions
    - Carer / family member / friend
    - Medical person
    - Another person affected by cancer
    - Researcher

8. Bearing in mind that some of the issues that are important to you might also be upsetting to talk about – do you have any advice for a researcher in terms of…..

- Methods to use
- 'No-go' areas
- Other

9.Your views and experiences could help to improve the health and support services for people like you but might not actually benefit you personally. Bearing this in mind, how do you feel about taking part in research?

10. Is there anything else that you would like to talk about?

11. Finally, how did you find taking part in this focus group?

- What could have been improved
- Suggestions regarding location, etc.