Key informants

Group informant is in researcher/research governance or ethics/care home manager/owner/officer of patient/carer organisation.

Introductory statement

It is well recognised that we now have an increasingly elderly population and these elderly people are now major consumers of health care. Historically older people have been excluded from health research, often due to the complexities of getting old. However, it is our belief that, if we want to ensure that the physical and psychological needs of the elderly are addressed to ensure a good quality of life into old age; then research should be inclusive of this population.

- To what extent do you agree/disagree with this statement and why do you feel this way?
  - How important do you think it is for research aimed at benefiting the health of our elderly to be inclusive of elderly people?
- If you agree that health research for the elderly should be inclusive what is your opinion of this research being carried out in the different setting in which this population can be found? (e.g. hospitals, residential/nursing homes care homes, sheltered accommodation or own home/community) [*note*: expand and explore the different settings]
- What, if any, has been your personal involvement in research with the elderly?
  - Participant, consultee, researcher, ethics advisor, hosting research.
- What do you think are the main difficulties in conducting this type of research?
- What do you think are the ethical difficulties in conducting this type of research?
- Many people in residential accommodation, and some people living in their own homes have cognitive impairment and some may lack capacity to give consent to take part in the research or find it difficult to understand the study information. How do you think researchers should approach this problem?
  - Reference to the law/The Mental Capacity Act.
  - Reference to proxy decision-makers or advisors on capacity.
  - Tailoring the consent process, information sheets, time for considering, involving others in the process, formal assessments of capacity, acting in their best interests.

Cluster randomised trials involve testing an intervention at a group level so individual consent is not required but consent from a 'keyholder', such as the manager of a residential home or a GP practice.

- Do you think this type of research raises particular concerns? If so can you elaborate?
- Does it make a difference if the population concerned includes individuals who are cognitively impaired/lack capacity?

Researchers/academics

- What challenges have you faced as a researcher working with this population?
- How have you handled the recruitment and consent processes with an elderly population?

General questions

- If you were the relative of person unable to decide for themselves and were asked to advise whether they should be included in some sort of health research project how would you feel about this?
  - How would you make a decision?
  - Would the type of study influence your decision? (e.g. drug trial, exercise/fitness intervention)
  - Would you act with or without consulting your relative?

- Consider that you are an elderly resident in a residential home and you have been approached by a researcher from a university who is carrying out a research study that it is hoped will improve elderly care in the future.
  - What would you want to know to help you make a decision?
  - Would you want your family to be involved in this decision? Or indeed to make the decision for you?

- If in the future you were unable to make decisions for yourself how would you feel about participating in research?
  - Are there types of research you would want to take part in?
  - Are there types of research you would not want to take part in?
  - Who would you want to make the decision for you?