

Mylife

a case study of the ethics of user involvement in field trials across Europe

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Innovations
in Dementia



MyLife

- For people with memory problems
 - remain orientated in time
 - in control of their appointments and social lives for as long as possible
- Design based on user control
- Not to involve end users would be unethical



Ethical framework

- Privacy
- Autonomy
- Integrity and dignity
- Reliability
- E-inclusion
- Role of technology in the society
- Equality of access

Risk matrix

- Recruitment
- Information to users
- Field trials (system)
- User tests (HCI)
- Communication with users
- Focus groups
- Dignity /privacy
- Exit strategy
- Data storage
- Use of results
- After-trial use of equipment

European Differences in Ethics Approval - UK

- Summary of project to Social Care Research Ethics Committee:
 - Project not considered Research
 - No application required

European Differences in Ethics Approval - Germany

- Meeting with *Berlin Data Protection Officer*:
 - Fine with survey to include people with dementia.
 - Specified must work according to the general principles of research: making data anonymous, store personal information safely (address, name, code plan which relates participant numbers to names) safely and separate from the data.

European Differences in Ethics Approval - Norway

- Recommendations from the National Committee for Research Ethics in Science and Technology:
 - Not include people with dementia, only memory problems
 - All potential participants should be given same information about the project
 - Not to ask about willingness to pay (research v marketing investigation)
 - Clear who is funding
 - Details about handling of personal information submitted to the Norwegian Social Science Data Services.

New methods – Issues to overcome

- Language problems
- Memory problems
- Lack of confidence
- Only hearing carers

Different methods

- Interview rather than questionnaires
- Audio and video recording
- Observation
- Weighting results equally in analysis
- Adapting existing methods – eg
Think Aloud protocol

Cooperative evaluation – adapting the Think Aloud protocol

- Participants should not feel that they are being tested.
- Participant is encouraged to see himself as a collaborator in the evaluation.
- Enables the researcher to ask questions and clarify points with the participants during the tasks.
- Researcher can give hints and tips.

Reliance on a system in development

- MyLife as a part of everyday life
 - “It's funny though, we never realised how much he used the MyLife until now he hasn't got it and now he feels lost without it!”
- Costs of the tablet and app

Exit Strategy

- Users can exit the project at any time
- If users exit before the end of the trials, the equipment will be returned
- At the end of the trials, users have the opportunity to keep the equipment.

Thank you

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