Necessity or Nuisance?

Involving cancer patients and carers as co-researchers: Learning from the Macmillan Listening Study

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Macmillan Listening Study principal aims

- To undertake a national exercise exploring the views people affected by cancer have about cancer research
- To undertake a national exercise identifying the research priorities of people affected by cancer

US National Cancer Institute consultation on views of the public about cancer research (1997)

Participants supportive of cancer research but:

- Participants felt public has little access to information on research except when efforts are highly successful
- Egos were cited as possible reason for withholding information from the public and other researchers
- Although participants could name benefits for research – there was a feeling that the pace was not rapid enough
- Few were familiar with research terms and held misunderstandings of terms such as ‘biomedical’ research

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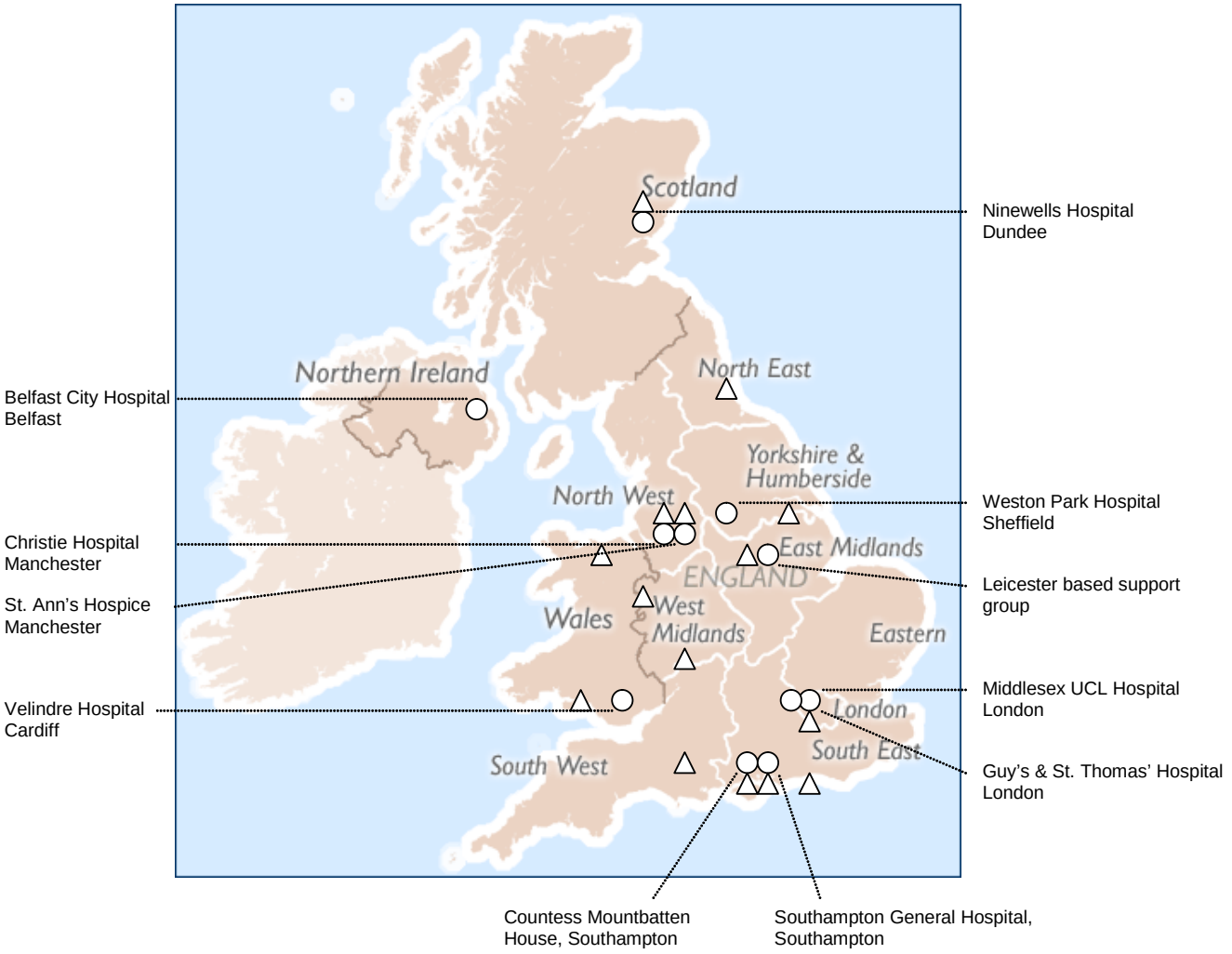
Macmillan Listening Study
User Reference Group

- 25 members
- 11 male / 14 female
- 3 carers
- No ethnic minorities
- No palliative care representatives
- All members from England and Wales

Location of Co-Researchers



○ - Participating Sites

△ - Co-researcher Representation

Patient and Carer Co-Researchers

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Patient and Carer Co-researcher Training

- General background to research methods
- Training on focus groups
- Further discussion and refinement of the consultation group question schedule
- Mock focus groups
- Distance learning
- Listening to consultation group recordings and reading transcripts

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Data Collection Process

- Participants discussed involvement in and knowledge of research and perceptions of cancer research
- Research topics written on ‘post-it’ notes
- Topics grouped into themes by participants
- Votes cast
- Priorities read to group and discussed
- Evaluation questionnaire

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Data Analysis Process

- Two data types generated - priority tables and transcripts
- Thematic analysis conducted on both data types
- Analysis conducted independently by members of research team and co-researchers
- Analyses compared to assess levels of agreement

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Benefits of co-researcher involvement

- Ensures the appropriateness of Patient Information Sheets and research questions asked
- Breaks the researcher / researched divide: Participants felt more at ease in participating in research led by peers
- Patient and carer co-researchers used their experience and knowledge to prompt participants and follow up issues
- Patient and carer co-researchers used their experience to remain aware of the needs of participants.
- Participants discussed a range of research interests rather than focusing on what they thought were the interests of ‘experts’.
- Permitted a comparison of themes generated from the analysis conducted by non-academic researchers.

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The Challenges of Involving Co-Researchers

- Ethics, R&D and Governance
- Cultural Issues
- Practical Issues
- Methodological Issues

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Ethical, R&D and Governance Challenges

- Data Protection
- Indemnity Insurance
- Central Office for Research Ethics Committees
- Research Ethics Committees
- Protocol Peer Review Committee
- Honorary Contract

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Data Protection Issues

- Where will patients and carers have access to data?
- How will patients and carers receive data?
- Will data be anonymised before the co-researchers receive it?

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Ethical Issues

- Will involving patients and carers as co-researchers affect the rigour of the research?
- Should patients and carers have access to other patients and carers in a research context?
- Should patients and carers have access to patient and carer data?

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Ethical issues concerning co-researchers

- Are co-researchers fully informed about the study before agreeing to participate?
- Are co-researchers able to ‘opt out’ of the study?
- Are co-researchers well enough to participate?
- Are co-researchers over-committed with other research?
- How will co-researchers’ details be kept?
- Will co-researchers’ expenses be met by the project’s budget?
- Will co-researchers become distressed by taking part in research?
- Will co-researchers be provided with counselling support where necessary?

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Cultural Challenges - views expressed during the ethics process

- ‘Patients and carers do not have sufficient knowledge to be able to comment on research priorities’
- ‘The priorities of those with qualified medical experience should not be neglected’
- ‘There is a potential for the quality of the research to be affected by involving co-researchers’
- ‘Cancer patients are too ‘vulnerable’ to participate in research of this nature’

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Practical Challenges

- Time and financial cost of patient and carer involvement
- Logistics of providing training for co-researchers distributed across the UK
- ‘Multiplication’ of ethics, R&D and governance procedures
- Organisational challenges of focus groups
- Co-researcher payment and its impact on benefits

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Methodological Challenges

- Impact on the quality of research data
- Formulating the model of ‘co-moderation’
- Negotiating the researcher / researched divide - can you go too far?
- Managing differences in data analysis - is it an issue?
- Evaluating the impact of co-researcher involvement

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Recommendations for ethics committees and governance bodies

- Training on ethical issues pertaining to user involvement
- Training on user involvement approaches and related methodologies
- Streamlining and consistency of R&D procedures
- Ethics and governance processes should be proportionate to the level of risk associated with a study
- Prejudices should be challenged

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Recommendations for researchers

- Allow sufficient time and financial resources to support the involvement of patients and carers
- Establish clear terms of agreement with co-researchers before the start of the study
- Be flexible with the research design to permit effective patient and carer involvement
- Negotiate ethics, R&D and governance requirements well in advance of study commencing
- Create opportunities for effective peer support
- Establish effective education support and supervision for co-researchers