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Small Voices Big Noises

Lay involvement in health research: lessons from
other fields

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Executive Summary

SECTION 1

1. Introduction

This project was undertaken in association with Folk.us (the Forum for Collaboration with Users in Research) at Exeter University. The study was commissioned by Consumers in NHS Research, an advisory group to NHS Research and Development, committed to ensuring that consumer involvement in research and development leads to improvements in the way that research in the NHS is prioritised, commissioned, undertaken and disseminated. Further funding was received from the Centre for Evidence-Based Social Services (CEBSS) at Exeter University.

Aims of the study

The project was designed to investigate the extent and nature of the involvement of lay people in research in fields other than health, and to highlight lessons that can be transferred to health research.

The aims have been achieved by 'scoping' or searching the literature for books, articles and reports which describe approaches to research or actual research projects where lay people have been actively involved. Over 500 pieces of literature have been included in a database, details of which are available for interested professionals and lay people.

Eight research projects that actively involved lay people were visited and summarised as 'case studies'.

The production of the main report has been a collaborative effort, involving members of Folk.us, the Steering Group of lay people and professionals from different fields, and the project team.

The report is in three sections: a review of the literature and case studies, an overview of the theoretical background to development of lay involvement in research; lessons learned and implications.

2. Fields

The scoping exercise revealed projects and background reading within the fields of Social Care, Education, Public Health/Health Promotion, Community Development UK, Housing/Regeneration, Agriculture/ Environment and Development Overseas.

Groups of people who may particularly benefit from being involved in research were identified and considered within each field. These are: carers, young people, older people, people with physical or sensory disabilities, people with learning difficulties, people with mental health problems, homeless people, and people experiencing poverty.

The topics investigated by research projects were generally related to services provided, or in the case of community development and overseas development, about the ways in which quality and conditions of life could be improved. Traditional questionnaires and interviews were the most frequently used methods across most fields. A popular method in community development and overseas development was participatory appraisal.

Professional-led and lay-led research projects were identified as well as some where those involved worked in collaboration or partnership.

3. Case studies

Eight case studies were identified to bring to life the process of involving lay people in research.

The case studies:

1. **Barrow Community Gym** – evaluation of gym for mental health service users.
2. **Finding Out** – people with learning difficulties found out about the experiences of other self-advocacy groups.
3. **Briardale Community Centre** – local people were recruited to carry out a door-to-door survey of people's wishes for facilities in the new community centre.
4. **Preston Road Estate** – local people used participatory appraisal to find out what needed to be done to improve quality of life on the estate.
5. **Holderness Youth Initiatives** – young people used participatory appraisal to investigate a number of issues relevant to them and their community.
6. **Totnes Traffic Appraisal** – local people formed a group to try to find solutions to the local traffic problems.
7. **Barriers to Independence** – older people are currently investigating the barriers to independence for people of their age.
8. **Alternative Choices** – an investigation into alternative strategies of coping with mental health problems.

4. Helpful hints for lay involvement in research

This chapter explores how lay people can be engaged in research, how research can lead to sustainable outcomes for people and how lay people can be involved in different types of research in other fields.

Some of the more innovative methods being used in participatory research are outlined. These research tools are often 'visual' in nature and do not rely on a shared language between researcher and researched. They offer an alternative to conventional techniques, and can be more enjoyable to use, when motivating people to become involved is an important factor.

Practical tools for monitoring, evaluating and reflecting upon participatory research are offered. These record the balance, level and quality of involvement and participation through the research process.

5. Factors that help or hinder lay involvement in research

Specific factors that helped or hindered lay involvement in research are identified from the literature and categorised under a number of headings:

- **Attitudes** – Attitudes of professionals towards lay involvement in research act as a barrier in a number of ways. Where the funding or commissioning body have a positive attitude towards active lay involvement, this acts as a facilitating factor.
- **Diversity** – The diversity and complexity within and between groups of lay people is often overlooked. However, there are systematic techniques that can be used to ensure all 'stakeholders' are considered in a research project.
- **Knowledge** – it is recognised that lay people lack knowledge about research, but professionals may lack vital local knowledge which contributes to the identification and solution of local problems. Giving equal value to both types of knowledge can facilitate the participatory research process.
- **Power** – the power relationships between researcher and researched can lead to the dominance of agency priorities. Awareness of power differentials and a desire to share power can facilitate lay involvement.
- **Resources** – lack of time and money are frequently cited as barriers to active lay involvement in research. More time and money are needed to engage lay people, and to allow for change in the agenda as the process proceeds. Some agencies encourage active participation in research through their funding application procedures.
- **Values** – professional values require expansion in some areas. Amongst these were issues about the 'protection principle' on which ethics committees operate, which does not encompass the potential for empowerment of individuals through research. Honesty, openness and trust were identified as factors that facilitated the participatory research process.

SECTION 2

6. The bigger picture

Different approaches to research are adopted by different groups of people. Whereas scientific research tends to rely on quantitative methods, research involving lay people in their communities may also employ qualitative methods. The approach used depends on the questions being asked. More important in participatory research is that the balance of power is shared between partners. There is also a greater emphasis on implementation and action.

The purpose of lay involvement is explored. Making a practical difference to people's lives, empowering

individuals and communities and improving the quality of research and its outcomes are identified as important factors.

Decisions about which lay people to involve in the research process create difficulties around the nature of 'community' and the 'representativeness' of community members. The diversity of communities and the meanings of representativeness are discussed.

Ideas about lay involvement have undergone considerable changes in the past decade. We explore the different principles underlying the labels given to lay people, including consumers, partners, citizens and stakeholders.

The development of lay involvement in research and development in other fields started at different times and for different reasons. In community development, both in the UK and overseas, it began in the early post-war decades because of the realisation that poverty was not being eradicated by top-down policy directives. In social care, strong voices from the 'user movement' influenced lay involvement particularly during the 1980's and 1990's.

Acknowledging the power relationship between those setting the research agenda and lay people acting as research participants has implications for the empowering potential of research. Looking at different 'models' of empowerment highlights differentials in power and suggests ways of overcoming them.

Lay and professional views of the world are expressed through different vocabularies and knowledge bases. This has implications for the language used in research.

Contexts or settings which facilitate or hinder lay involvement introduce the notion that social, political, economic and cultural contexts play a vital part in determining the extent to which lay people can be involved in research. Often the culture of organisations dictates the potential for lay involvement. More democratic and philanthropic organisations can facilitate lay involvement, whereas the structures of rigid hierarchical organisations erect barriers.

SECTION 3

7. Lessons learned and recommendations

These are categorised under the following headings: Context, People, Process and Resources.

Context

LESSONS: The findings highlight the importance of the political philosophy and context of research.

RECOMMENDATIONS:

- procedures and mechanisms should be put in place by funders and sponsors of health research to ensure that commitment to lay involvement in research is turned into a reality. Such procedures already exist within government departments such as the Department For International Development (DFID) and the Department of Transport, Local Government and the Regions.

People

LESSONS: the importance of shared values, mutual respect and trust, and common language in negotiations between partners about problems and solutions is highlighted. Needs for clarity in the aims and expectations of research and in the roles and responsibilities of partners are also noted. Issues of 'representativeness' of lay people were overcome where small-scale projects were undertaken.

RECOMMENDATIONS:

- A glossary of research terms (by lay people, in collaboration with professionals) should be produced. A clear definition of 'lay involvement' should also be produced and included in Research Governance so that professionals and lay people undertaking research know exactly what is meant by the term.
- Commitment to ensuring that research makes a difference to people's lives in a sustainable way should be built in to the requirements of funding agencies, following the example of DFID. The Department of Health and other funders should develop strategies linking health research outcomes more closely to the development of future services.

Process

LESSONS: Flexibility in several aspects of research is required. This includes the methods used, the direction of the research, which often evolves and changes when lay people are actively involved, and make it possible for people to be involved at all stages of the process.

RECOMMENDATIONS:

- The process of gaining ethical approval should be simplified and procedures changed so that applications can be received from lay people. Ethics committees should broaden their criteria for approving projects to incorporate

empowerment as well as protection of individuals.

- Everyone should be involved as early as possible in the research process, so that both lay people and professionals feel that they 'own' the project and will be committed to it. Where lay people are involved as steering group members, they should be in equal proportion to professionals.
- Researchers should consider using other research methods as alternatives or complementary to traditional survey techniques. It is important to respect and make use of local knowledge, as lay people are experts of experience. Every day informal research often brings up more practical issues and solutions.
- Researchers should aim to make meetings with lay people informal. Providing lunch and holding them in a location familiar to those involved, for example, can facilitate relaxed discussion and put people at ease.
- Small-scale projects may overcome the issue of representativeness. NHS R & D should develop an equivalent to meta-analysis to bring together the results of similar small, local projects.

Resources

LESSONS: flexibility of funding and the time allowed to undertake participatory projects was highlighted, as was the need for support in a variety of forms and training of professionals and lay people for a number of different purposes.

RECOMMENDATIONS:

- Research funders should start taking into account the extra time and money needed when involving lay people in research. Longer lead-in times for building up relationships should be allowed for, as well as the extra expense of communicating with lay people throughout the research.
- Researchers should consider the resources required for implementing their research findings early in their planning. Sponsors and funders should ensure that sustainability is built in at the very start of the project, so that implementation of results and on-going support are incorporated into the project design.
- Researchers should always provide payment of lay people for work undertaken and out of pocket expenses. Practical support in terms of transport, accessible meeting places etc should also be provided, along with emotional support, such as advocacy, or facilitation for creating, sustaining and managing relationships.
- Health research and development support organisations should consider appointing a liaison officer with responsibility for guiding participatory research and supporting lay people.
- People expected to facilitate participatory research should receive specialist training. Training courses for health professionals should incorporate lay voices and cover ideas and methods for lay involvement in research and service development.

The full report can be downloaded in pdf format from the Consumers in NHS Research website, at <http://www.hfht.org/ConsumersinNHSResearch>

A booklet has also been produced, aimed at lay people who might like to become involved in research.

If you would like a printed copy of the full report, booklet or any further information, please contact us at

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