

Small Voices Big Noises

Lay involvement in health research: lessons from other fields

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A booklet aimed at lay people who would like to get involved in research has also been produced using the information from this project.

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Contents

	Page
List of Tables	iv
The Research Team	v
Acknowledgements	v
Executive Summary	vi
Abbreviations	ix
Definitions	x
SECTION 1	
1. Introduction	1
2. What we found in each field	4
3. The case studies	23
4. Helpful hints for lay involvement in research	34
5. Factors that help and hinder lay involvement in research	55
SECTION 2	
6. The bigger picture	69
SECTION 3	
7. Lessons learned and recommendations	101
References	113
Glossary	125
Annexes:	
A. List of databases and information sources	126
B. Key words used in searches	127
C. Questionnaire sent to user groups	128
D. Framework for choosing case studies	131
E. Pro forma questions for case study visits	132
F. Details of case studies	133
G. Models of participation	141

List of Tables

Table	Page no.
1. Summary of literature found in Social Care	7
2. Summary of case studies	25
3. Levels of lay involvement in the research process	26
4. A single dimension framework for analysis of balance of participation in health research	49
5. Participation at different stages of the project cycle	50
6. Quality of participation matrix	52
7. Quantity of participation table	53

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The research was undertaken in association with Folk.us, the Forum for Collaboration with Users in Research, at the School of Psychology, Exeter University. Folk.us supports lay people who wish to be actively involved in research.

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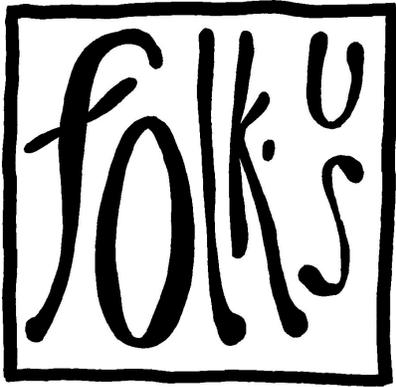
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Small Voices Big Noises

Lay involvement in health research: lessons from other fields

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.

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 which actively involved lay people were visited and summarised as 'case studies'.

The production of the 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 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 are 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.

The group of research approaches known as 'participatory research' is identified as particularly useful. 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

Lessons and recommendations are highlighted based on the search of the literature and visits to case studies. These are categorised under the following headings:

- **Context** –highlights the importance of the political philosophy and context of research.
- **People** –emphasises the importance of shared values, and common language in negotiations between partners about problems and solutions. Needs for clarity in the aims and expectations of research and in the roles and responsibilities of partners are highlighted. Issues of 'representativeness' of lay people were overcome where small-scale projects were undertaken.
- **Process** – a major lesson was the need for flexibility in several aspects of research. This included 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.
- **Resources** – 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.

Overall, ideas and methods for active lay involvement from other fields are practical and applicable to health research. These approaches may help to ensure that lay people are empowered through research that directly leads to real improvements in services and in their lives and circumstances.

Abbreviations

BMJ	British Medical Journal
CARE	Co-operative for Assistance and Relief Everywhere
CEBSS	Centre for Evidence-Based Social Sciences
CERES	Consumers for Ethics in Research
DETR	Department of the Environment, Transport & the Regions
DTLR (formerly DETR)	Department of Transport, Local Government & the Regions
DFID	Department For International Development
DOH	Department of Health
Folk.us	Forum for Collaboration with Users in Research
HYI	Holderness Youth Initiatives
MRC	Medical Research Council
OFCOR	On-Farm Client-Oriented Research
PA	Participatory Appraisal
PAR	Participatory Action Research
PRA	Participatory Rural Appraisal
R & D	Research & Development
RCT	Randomised Controlled Trial
RDSU	Research and Development Support Unit (NHS)
SLA	Sustainable Livelihoods Approach
SRB	Single Regeneration Budget
SSRG	Social Services Research Group
USAID	United States Agency for International Development

Definitions



‘Consumers in NHS Research’ refer to lay people as consumers.

There are also other terms used in the literature (for example, ‘service users’, ‘local people’, ‘citizens’) to describe ordinary folk. The decision to use the term ‘lay people’ has been made because it is all-encompassing, whereas others refer only to some lay people in some settings. Deliberation with the project steering group led to the definition of this and other key terms we use in this report.

‘Lay’ (involvement): *Becoming involved through ‘life experience’ rather than any specialist, professional, academic or practical training. Lay people may include service users, carers, patients, clients, citizens (etc) or may represent service users.*

Involvement: *Having an active influence on some or all parts of the research process.*

Research: *A process of collecting, ordering and evaluating information so as to provide further understanding, and/or new knowledge, and/or a basis for decision making and action or change.*

Participatory Research: *Research in which power is shared so that it is carried out ‘with’ and ‘by’ lay people rather than ‘on’ them. This may employ a variety of methods.*

Empowerment: *A process by which people gain increasing control over their lives and circumstances.*

SECTION 1

1. Introduction

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever does.” (Margaret Mead, Social Anthropologist)



In recent years, the involvement of lay people in shaping services has become central to government policy in the public sector.⁶³ With the current emphasis on evidence-based practice, lay involvement in research is an important way for people to influence practice within health and social care. Yet there is still a long way to go before lay people are consistently involved across all aspects of service research, development and delivery.

This study was commissioned by ‘Consumers in NHS Research’ to find out what lessons can be learned from other fields to enable health research to be conducted *by* and *with* lay people, or by lay people in partnership with professionals.

Aims of this scoping study

- ◆ To collect examples of published and unpublished material on lay involvement in research within and across the fields of health, social care, overseas development and UK community development at a local, regional and national level
- ◆ To identify other fields in which lay people have been actively involved in research

- ◆ To produce a set of case studies of examples of lay involvement in research across fields
- ◆ To produce a report which summarises information about lay involvement in research across fields, with guidance and consideration of implications for NHS Research and Development
- ◆ To do this work in a participatory way, with collaboration between professionals and service users and carers, and in co-operation with Consumers in NHS Research.

A note about us..

It is important that we should make clear 'where we are coming from'. It is fair to say that all those involved in this project are committed to the principle of collaborative and partnership research. Members of the steering group include lay people as well as professionals working in research in health, social care and overseas development. Through this we hope to encourage ownership and empowerment through lay involvement, and to educate ourselves and enlarge our different views about research and involvement.

Notes on our methods

A 'scoping' project provides a wide-ranging view of relevant research. The examples, case studies and reviews of the literature discussed in this report span many fields and it would have been impossible in the time available to produce a systematic review of them all. Our search, however, has been extensive. Readers are referred to our reference list and suggested reading throughout the report for further information on how lay involvement in research can be achieved. In general, examples from health have been omitted as the purpose of this study was to look at other fields, but there are examples of

readings and research which are related to health, particularly where a study spans more than one field, such as health *and* social care.

Finding your way around the report

Throughout the report we highlight in bold and italics key messages about lay involvement in research. ***These are either common issues that appear frequently in the literature, or particular ideas that may be new to health research.***

This report is presented in three sections:

- Section 1 contains practical information about how we undertook the study, what we found and the lessons we have learned.

- I. Section 2 fills in the background to lay involvement, ideas about lay involvement and research and explores the context in which it occurs.

- II. Section 3 summarises the lessons learned and includes recommendations for future research and practice.

2. What We Found in Each Field

This section includes:

- ◆ Information about the searches we made
- ◆ What we found within each field:
 - research project or background
 - common methods used
 - what topics have been covered
 - the degree of involvement of lay people
- ◆ What lay people get out of becoming involved in research

The fields we investigated were:

Social Care

Education

Public Health/Health Promotion/Education

Community Development UK

Housing/Regeneration

Agriculture/Environment

Overseas Development



Information about the searches we made

The main focus of our search was for the period from 1995 to the present (for published and unpublished material), but we followed up secondary references, particularly in looking for background information, which extended beyond this period (for more information about the searches we made see Annexes A and B).

Many write-ups of research involving lay people do not get published in forms that are recorded on databases. We therefore attended

seminars and met people with an active interest in this area, in order to learn of such projects. Even when identified, it was sometimes difficult to obtain copies of reports that were published in limited numbers. This was particularly the case with reports from charitable organisations.

A questionnaire (see Annexe C) was sent out to 190 user groups on the local CEBSS mailing list, asking if they knew of, or had carried out, research involving lay people. We received responses from 23 groups telling us about research in which they had participated.

In all, the searches resulted in the identification of over 500 articles, books and reports. For the purposes of this study, we focused on literature that:

- cast light on ways in which research with active lay involvement may be different to more conventional research which does not have the tradition of actively involving lay people
- clarified and expanded our understanding of what we mean by 'lay', 'involvement' and 'research'
- highlighted factors that helped or hindered active lay involvement in research
- conveyed lessons which may be transferable to health research
- taught lessons about how methods of achieving general participation may be applied to the research process
- identified examples that might be considered good practice in active lay involvement in research, i.e. could help develop criteria for appraisal of projects involving lay people
- illuminated a range of ways of achieving lay involvement in research across different fields.

Research projects were only included if they actively involved lay people at some or all stages. We aimed to identify research projects initiated by lay people and/or professionals.

The categorisation of the literature into the chosen fields seemed, at first, to be a straightforward task. But once the gathering of information had started, it became clear that it would not be so simple. Many of the topics covered by the literature spread across two, if not three, fields plus there was debate about what field a project would come under if it was funded by an agency in one field, but actually investigated issues in another.

We have made a distinction between 'projects' and 'background' material. 'Projects' are write-ups of specific research projects. 'Background' material is any other literature obtained which increased our understanding of lay involvement in research, including publications containing details of how to involve certain groups of people, ethical issues and research methods as well as descriptions or reviews of a number of research projects.

We considered different groups of people within each field, in order to find out whether they become involved in certain areas of research, whether different research methods are used or whether people become involved in different ways and at different stages. We considered:

- Carers
- Young people
- Older people
- People with physical or sensory disabilities
- People with learning difficulties
- People with mental health problems
- Homeless people
- People experiencing poverty

We found examples of people from all the above groups being involved in research except for carers. Henwood's report 'Ignored and Invisible' highlights the fact that carers are often overlooked in consultations about services⁹⁶, as well as in research.

For more information about the issues surrounding working with different groups of people, see: Rodgers¹⁶⁹ and Heller⁹⁴ (people with learning difficulties); Hill⁹⁸, Adams⁴ and Johnson¹¹⁰ (young people); Thornton¹⁸⁸ (older people); Barnes and Mercer¹⁵ (disability).

What We Found

Social Care

In addition to the literature discussed below, we found 25 books and articles that were about general aspects of involving service users. These most often described ways people could become involved and the issues that might arise, as well as the influence of current policies on service user involvement.

Table 1: Summary of literature found in Social Care

Group	No. of Projects	No. of Background References
Young People	9	22
Older People	5	7
Mental Health	14	17
Physical/Sensory Disability	10	16
Learning Difficulties	17	18

Methods used: **Across all groups of people, questionnaires, some of which were administered as interviews, were favoured as a research technique.** Sometimes focus groups were also used to draw out key topics and further investigate certain issues.

Topics covered: Generally, the research in which people became actively involved was about the services they used or their experiences of these services. Background literature tended to focus

on the issues around working with these particular groups and the best ways of involving them.

Young People

Degree of Involvement: In most cases, young people had been involved from the start of the project, had worked on questions to be asked and carried out the interviews themselves. All the projects were initiated by professionals, but in most cases, the young people were given considerable control over the process whilst the professional provided support.

Example from the literature: West et al (1995) ²⁰⁹	Field: Social Care Group: Young people
<p>Young people from five cities, themselves care leavers, were recruited to interview their peers as well as social services' staff about experiences of leaving care. They discussed key issues and devised a questionnaire. They collected the information, analysed it and suggested preliminary findings. Time did not allow the young people to write up the report, but the researchers who did write it considered their drafts. The success of the project was considered to be that the 'right' questions were asked and also that the 'real' answers were received.</p> <p><i>"Being interviewed by a care leaver...I thought it was good, I thought it was the best idea they could have come up with, because it is better being interviewed by someone who has been in care themselves than it is a complete stranger who doesn't know what they are talking about."</i> Interviewee.</p>	

Older people

Topics covered: Projects specifically aimed at investigating older people's needs were most common, for example the 'real' cost of living for pensioners¹⁵⁴.

Degree of involvement: In the majority of projects, older people had an active influence on most of the research process, with some run by older people's groups or with proactive steering groups comprised of older people. In only one project were older people solely involved with interpretation of the results.⁶¹

Example: (personal communication)	Field: Social Care (& Health) Group: Older people
The three-year 'Buying Time' project in Exeter started in 1999. The idea of involving older people in this study of rehabilitation services was discussed with Age Concern only after the methods had been set. It was jointly agreed that including people at this late stage would be difficult to do well and would risk being tokenistic. However, a new grant has just been approved for a qualitative study of user views about a rehabilitation unit. This time, older people are being recruited to the steering group and will be involved as much as possible in the research process.	

Mental Health

The majority of research projects were from the UK, but a lot of the background information came from the USA and Canada, where the 'survivor' movement has been strong for many years.

Topics covered: Alternative coping strategies⁷⁵ and the readmission of people with schizophrenia⁵⁸ were investigated as well as mental health services.

Degree of involvement: Five of the projects were 100% user-led, a professional body had usually initiated others.^{50 75 97 170 208} **Service users became involved at an early stage in the research process, often taking part in the planning as well as design of the work before sometimes moving on to help with data collection, analysis, dissemination and implementation. Some felt empowered by the process, and for some it led to paid employment.**¹⁷⁰

<p>Example from the literature: Davidson et al (1997)⁵⁸</p>	<p>Field: Social Care & Health Group: Mental health service users</p>
<p>Davidson et al describe research that they carried out with patients suffering from schizophrenia. They wanted to learn the reasons that many patients experience numerous readmissions and from that, think about possible new interventions that could be more effective in helping patients to remain in their community. Past patients were tracked down and invited to become involved. Those who agreed were interviewed individually, then took part in a discussion group to look at the main themes that came out, translating these into possible new interventions.</p>	

Physical or Sensory Disability

We learned of many organisations campaigning for greater involvement of disabled people in service planning and research. However, surprisingly few *published* examples of research projects came to light from our searches.

Topics covered: Two projects were evaluations of user-led services for those with a disability.^{16 218} One local group had investigated several issues for people with sensory disabilities.^{28 29} There was also

one project which involved disabled people in defining research priorities in wheelchair design.³³

Degree of involvement: People became involved at a variety of stages in the research process. Several projects were commissioned by user-led organisations, so disabled people made decisions about the research question. ***Very often, a professional under the guidance of a steering group of lay people carried out the actual research.*** Disabled people did, however, sometimes have active involvement throughout the research process.

Example from the literature: I Am In Control (1996) ²¹⁸	Field: Social Care Group: People with a physical disability
The Wiltshire & Swindon User Network's evaluation of a local independent living centre actively involved disabled people from the very start of the project, as an advisory group, then through data collection and analysis, to dissemination. Different people took on different roles but disabled people controlled the research at all times.	

People with Learning Difficulties

Most of the projects had taken place in the UK, three in Australia and one in the USA.

Topics covered: Different topics covered by projects were, how it feels to be labelled 'learning disabled'¹⁵² and good ways of involving people with learning difficulties in research.⁹⁴

Degree of involvement: People were involved at various stages. Three projects were led by people with learning difficulties, who were therefore involved at all stages.^{34 74 87} In professional-led projects,

people became involved after the research question had been decided, but often had some influence over the precise questions asked and the manner in which they were presented. There were also projects that had steering groups or advisory panels with members who had learning difficulties. Two projects involved people as co-researchers, taking part in data collection and analysis as well as decision making.^{71 140} ***Lack of involvement at the initial stages of one project led to members of an advisory group feeling isolated.***¹⁸¹

<p>Example from the literature: Young & Ludwig (1996)²²⁵</p>	<p>Field: Social Care Group: People with learning difficulties</p>
<p>Young & Ludwig collaborated with people with learning difficulties and staff members to investigate satisfaction with services provided by an agency which employs people with learning difficulties in sheltered workshops. The team worked together to develop a questionnaire, making sure the <i>questions were presented in words that could be understood by people with all levels of learning difficulty.</i> Some of the people with learning difficulties interviewed other agency clients, recording the interviews for later analysis. The team reconvened to discuss interview transcriptions and to review a summary written by the research staff member. An important aspect of this project is that people with learning difficulties were involved throughout the research process. A special effort was made to make things understandable at all times, including the team redesigning a consent form so that all members of the group could understand the concepts involved.</p>	

Education

Number of projects identified: 8
Number of background references identified: 11

The lay people involved in educational research projects tended to be young people (pupils) or teachers. Teachers fit our definition of lay people if they become involved through their life experience of teaching rather than because of research expertise, when the research is about them or their work, or they will be affected by the results. The majority of projects took place in the UK, with a couple of examples coming from the United States.

Methods used: Survey interview methods and focus groups were the most common methods used as part of a Participatory Action Research (PAR) approach.

Topics covered: Projects tended to look at the effectiveness of certain teaching methods and student motivation.^{30 47 149 151} One project investigated gender-related issues in primary school pupils.¹⁰⁶

Degree of involvement: About half the projects were initiated by professionals and half by lay people (students or teachers).

<p>Example from the literature: Oldfather et al (1998)¹⁴⁹</p>	<p>Field: Education Group: Students and teachers</p>
<p>A 6-year participatory research programme investigating literacy learning motivation in students is described. One project within the programme was initiated by interested students who attended a residential weekend to discuss the proposed work, then returned to their schools to recruit teachers with whom to collaborate. They worked with their teachers through interviews and research-team focus groups to learn about good teaching practice and what affects pupils' motivation to learn. The teachers' perspectives of this collaborative approach to educational research were reported and the consequences discussed.</p>	

Public Health/Health Promotion

Number of projects identified: 16

Number of background references identified: 24

There is a fine line between Public Health/Health Promotion and Education and the wider field of Health. We chose to include literature that covered topics such as lifestyles that affect health, for example smoking and diet, as well as health needs and sexual health issues. Eight research projects came from the UK, with the rest coming from USA, Canada, Australia, Sri Lanka, and Africa.

Methods used: A variety of methods were used in the projects we identified. Interviewing was common, as was PA (see chapter 4 for description).

Topics covered: Several projects involved people from the local geographical community and focused on general health needs.^{90 78 55}

¹⁰⁷ Drug use and HIV/AIDS were also investigated in more than one example.^{91 182 214} One project focused on the perceptions of health that were held by people with learning difficulties,¹⁶⁹ another on the drug and alcohol problems faced by people with physical disabilities³² and another looked more generally at how to better involve older people in health promotion.²¹⁵

Many of the background papers described public health research to highlight their points, and covered general issues about involving the relevant people in such projects. We came across one very useful review of community-based research aimed at improving public health.¹⁰⁸

Degree of involvement: Two of the projects involved young people, and they were fully in control.^{91 107} More often, however, research had been initiated by professionals but the lay people involved were given ***strong voices in decisions about the research process, which led to personal feelings of control.***¹⁹²

Example from the literature: Williams et al (1999) ²¹⁴	Field: Health Promotion Group: Ethnic minority communities facing AIDS
In order to understand the cultural context of health behaviour related to HIV/AIDS, researchers worked with stakeholders from 6 ethnic communities in Canada to form regional research groups. Each group provided advice and guidance on the way to carry out interviews and focus groups and also suggested people who could be involved in this data collection as interviewers and as participants. Further to drawing out the key issues, members of the community were also involved in discussion about intervention design and implementation.	

Community Development UK

Number of projects identified: 14

Number of background references identified: 15

Methods used: Some organisations in Hull have joined forces to run the Hull and East Yorkshire Participatory Appraisal (PA) Network. They provide training in PA to local community development workers and community members, as well as any other interested parties from this country and overseas. We included three projects on our database although every piece of community development work in which they are involved includes community participation. Apart from the predominant use of PA in Hull, other projects tended to use traditional survey methods, sometimes incorporating face to face interviews.

Topics covered: No one group of people is usually targeted in a community development project, the aim being to involve a cross-section of the community and therefore a range of people in age, ethnic origin, gender and abilities. Many projects were 'community appraisals', a term used to describe projects which look at community needs and ask what improvements could be made.

Other projects investigated the requirements of local people for new community centre buildings^{177 105} or environmental issues affecting their livelihoods.^{112 8 122 145 176}

Degree of involvement: Nearly all the projects were professional-led or initiated by professionals. However, the community was often engaged early in the process, having active influence over the questions asked and the way that they were conveyed. People were less often involved in data collection and analysis, although many projects held feedback sessions in order to verify their findings and for local people to have a chance to make further comments. **Some**

participants reported life changing outcomes in terms of skills and social gains¹¹⁷, plus the ability to effect change in their communities.²⁰⁷

<p>Example from the literature: Gillespie et al (2000)⁸³</p>	<p>Field: Community Development UK Group: Local people</p>
<p>The Duthchas project in Scotland was set up to create sustainable development in rural communities. Within three communities local people and a number of agencies worked together to identify problems and solutions. As well as door-to-door surveys, participatory methods were used at public meetings so that everyone’s voice could be heard. However, some people found exercises such as individually writing ideas on ‘post-its’ irritating, (“Not more ‘post-its!’”) so it was important to keep people interested by asking what they were comfortable with and adjusting the methods used accordingly.</p>	

Housing/Regeneration

Number of projects identified: 3

Number of background references identified: 19

Methods used: As well as peer interviewing, more innovative methods involving painting and video documentaries were used.⁵

Yeich²²⁴ helped form a homelessness union that collected information about homelessness and then presented this to universities and conferences as well as campaigning for change.

Topics covered: Two projects involved homeless people looking into their situation^{5 224} and the other involved mental health service users researching their community’s housing needs.⁴⁰ The background

information provided us with guidelines on how to involve tenants in projects around their housing needs. **Two reports focused specifically on ways of involving older people.**^{114 104}

Degree of involvement: professionals initiated most of the projects, but actively involved lay people throughout most of the research process. Homeless people initiated one with the researcher providing only support and encouragement.⁵

Example from the literature: Akilu (1995) ⁵	Field: Housing Group: Homeless people
A researcher in Reading realised that the experiences of homelessness she witnessed whilst working in a shelter were not reflected in the results of a survey undertaken for her PhD. In an effort to engage homeless people and to gain an understanding of their perspectives of the experience of homelessness, a mural project was developed. Four men discussed what they would like to portray in the mural and then spent several afternoons painting. A vivid picture of homelessness and homeless people's desires was the end result, available for all to see. Significant changes also occurred in the men, leading to employment and greater commitment to changing their own situation.	

Regeneration is closely linked with Housing and with Community Development. We found nine pieces of literature providing background information about involving different communities in regeneration programmes, but nothing that described research projects as such. The Joseph Rowntree Foundation website of findings¹¹⁸ was a mine of information.

Agriculture/Environment

Number of projects identified: 2

Number of background references identified: 6

Methods used: The projects used Participatory Rural Appraisal (PRA).

Topics covered: The literature was largely based on work in developing countries and described Farmer Participatory Research which uses PRA amongst other methods. Professional agricultural researchers and farmers work together to improve and sustain farming practice. ***An important aspect of this approach is that the researchers or development workers acknowledge the research that the farmers already undertake informally.*** Okali et al¹⁴⁸ provide a good description of the methods and describe examples of successful partnerships. Biggs²⁵ reviews examples of scientific research involving farmers including Randomised Controlled Trials (RCTs). Campbell & Salagrama³⁹ discuss new approaches to participation in fisheries research.

Degree of involvement: The projects all aimed for collaborative working, with an emphasis on professionals and farmers working in partnership to find solutions.

Example from the literature: Bardolf (1996) ¹⁴	Field: Agriculture Group: Foresters & local people
PRA has been particularly successful in Vietnam. Projects have led to village development plans based around different agricultural issues such as forestry and livestock, as well as helping development workers to understand the current knowledge and capabilities of local people. Eventually, villagers successfully carried out their own PRAs with neighbouring villages and provided support to other communities.	

Development Overseas

Number of projects identified: 8

Number of background references identified: 15

Research projects were based in the USA, Canada, Sri Lanka, Nepal, Bangladesh, Vietnam and Guatemala.

Methods used: Semi-structured interviews using questionnaires were a popular research method. Projects focusing on community development were often examples of PAR, using a variety of techniques to seek answers to questions that were important to the community and to ensure ensuing action.

Topics covered: Many projects investigated general rural/ community development issues, such as quality of life. Some were more specific, for example looking at ways of coping with violence and the effects of war.¹³¹ Good examples of young people leading research projects were often supported by charities. The Save the Children Fund brought together street children, asked what they would like to find out about and then supported them in carrying out their own research in Bangladesh.¹²³ In other cases, children in Vietnam were supported in data collection in projects investigating the extent of child labour in rural and urban areas.^{186 187}

A great deal of participatory development work (as opposed to research) goes on overseas. A lot of the background literature has had a large influence on the practices of people working in community development in the UK (for example, the participatory appraisal method). One background publication was a manual of ways to encourage young people to become involved in urban development and planning.⁷⁰

Degree of involvement: In most cases, an effort had been made to include the community at every possible stage of the research process. The two American studies involved local people as a steering group that influenced all stages of the research, including the write-up.^{183 198}

<p>Example from the literature: Chataway (1997)⁴⁵</p>	<p>Field: Overseas Development Group: Native community</p>
<p>In Canada, Chataway spent time building up a relationship with a native Kahnawake Mohawk community in order to carry out research with them into issues that the community had identified ('what are the barriers to designing and adopting a new system of government in this community?'). This brought together conflicting political groups within the community and led to projects for reconciliation as well as meetings to discuss important community issues such as policing.</p>	

Many of the reports about community development UK and development overseas have a focus on **Sustainable Development**. A lot of the organisations working in developing countries now have a philosophy of attempting to make a sustainable difference to people's lives as a result of their projects. We identified some background information on these ideas, but no research projects specifically aimed at sustainable development without incorporating one of the other fields discussed in this section (see Chapter 4 for description of Sustainable Livelihoods Approach).

Items that were hard to categorise

There are many publications referred to throughout this report which cover a number of fields (e.g. 'Stepping Forward'¹¹¹ highlights research projects involving or led by children, covering education,

overseas development, health and more) or refer to specific topics such as ‘what is participatory research?’¹⁵³ We also included in this category theoretical information, for example about the nature of knowledge, and details of research methods that are not based on one particular field. Several have been suggested as further reading.

Health

We identified nearly 100 publications from health in the UK and overseas. These provided information about the current status of health research and background material about involving different groups of people, relevant across the board.

3. The case studies

We visited eight research projects that actively involved lay people in a variety of settings from the fields of social care and community development. The aim was to give ‘live’ examples of the experiences of those involved, and highlight the factors that either helped or hindered the process. The case studies offer a vivid illustration of many of the issues discussed in the literature.



How we chose our case studies

We drew up a framework (see Annexe D) for choosing case studies, with the intention that they should represent as full a scope as possible from:

- different *fields of study*
- different *stages in the research process* from design to dissemination
- different *levels of lay involvement*, from user-, community- or lay person-led through partnership research to professional-led, but all involving ‘active’ lay involvement
- different *research methods*, including surveys, focus groups, interviews and some of the more creative participatory techniques
- projects that were possible for us to visit in our time span.

We chose case studies from the research projects identified through literature searches and by following up leads through personal communications.

One of the researchers visited all eight case studies. She used a pro forma question sheet (see Annexe E for outline) to guide informal conversations with the lay and professional stakeholders of the

project, as well as sometimes the commissioners and funders. The main aim was to learn about people's different experiences of being involved in research. The summaries written about each project were returned to the people concerned for comment and any amendments requested were made.

Although at the outset it was intended to involve a lay person in visiting the case studies, in practice, this was only possible in one case. Members of Folk.us were asked if they would be interested in this, but some felt the project was rather abstract, and for others, the time commitment and travelling would have been difficult. This illustrates one of the barriers to achieving active lay involvement in research highlighted in the literature. In other words, we did not have sufficient 'lead-in' time to orientate lay people and enable them to gain a sense of ownership of the project.

What we found

The projects we visited came from the fields of community development and social care through availability rather than choice (see table on next page). We made a particular effort to identify potential case studies in public health, housing and education, but had no success. We learned of a couple of possible public health projects, but they tended not to involve true active participation of lay people.

We also tried to identify a case study that employed more conventional, experimental (or scientific) research methods that actively involved service users. However, within the UK, we were unable to locate any suitable projects outside of healthcare through our searches. We found a quasi-experimental research project in Scotland, where local people had been recruited to carry out data collection before an anti-smoking campaign started.¹⁵³ However, these

local people did not have any active influence on the intervention methods used or any other aspect of the research.

Table 2: Summary of case studies

Case study	Field	Group of people involved	Method used
1. Barrow Community Gym	Social Care/ Health	Mental health service users	Focus groups, questionnaire
2. Finding Out	Social care	People with learning difficulties	Group interviews
3. Briardale Community Centre	Community Development	Local people	Door-to-door survey
4. Preston Road Estate	Community Development	Local people	Participatory appraisal
5. Holderness Youth Initiatives	Community Development	Young people	Participatory appraisal
6. Totnes Traffic Appraisal	Community Development	Local people	Focus groups, observation
7. Barriers to Independence	Social Care	Older people	Individual structured interviews
8. Alternative Choices	Social Care/ Health	People with mental health difficulties	Focus groups

We assessed the degree of lay involvement in the case studies using a continuum that we describe in the next chapter (p.50). This moves through the four levels outlined below.

Table 3: Levels of lay involvement in the research process (adapted from Empowering People⁴⁶)

<p><i>Passive</i></p> 	<p>where lay people basically welcome the project proposals and support them but are not involved in the decision-making</p>
<p><i>Consultative</i></p> 	<p>where lay people are consulted by professionals about their opinions and/or knowledge</p>
<p><i>Active</i></p> 	<p>where lay people play the role of active partners of the project and assume increasing responsibility</p>
<p><i>Ownership</i></p> 	<p>where lay people are both willing and able to have or take control of the project</p>

Brief details of the case studies (one ‘visited’ via e-mail and telephone conversations) are included below. A more complete account of all the case studies can be found in Annexe F.

Case Study 1: Barrow Community Gym

This was an evaluation of a gym service for mental health service users. The level of involvement started as *Consultative* participation and evolved to an ongoing project where gym users had full *Ownership*.

Key lessons learned:

- ***Time and effort put in by researchers reaps rewards – friendships can be developed. Payment of expenses and working together over lunch also builds good relationships.***
- When participation is interrupted, professional researchers should provide continuity. Being accessible to user researchers as far as possible helps build confidence over time and break down the 'professional as expert' syndrome.
- ***It is important to set supportive mechanisms in place so that research efforts can continue after the departure of professional researchers.***
- ***Feeding back and reflecting on findings with lay people as often as possible demystifies the data analysis process.***
- Research should ideally build on existing skills and strengths. This means that the research process is less alienating and it may be possible to open up new potential.

Case Study 2: Finding Out

This was an investigation of how it feels to be labelled 'learning disabled' and to find out whether other groups of people with learning difficulties are in a similar position. The project was led and carried out by people with learning difficulties (*Ownership*).

Key lessons learned:

- ◆ ***Research can be fun and this definitely encourages people to become more involved***
- ◆ Gaining enough funding for lay researchers to be paid, leads to a feeling of self-worth and means that people do not have to give up their time for free.
- ◆ ***It is important to provide the results of research in accessible formats.***

Case Study 3: Briardale Community Centre

This was an investigation within the community into facilities for a new community centre. Lay people collected data, although they did not influence the questions asked (*Active involvement*). The outcome was a successful community-owned and run centre.

Key lessons learned:

- Planning *when* to carry out the research may be important – walking through the streets in the summer when the sun was shining was enjoyable.
- It is really helpful to have supportive partner organisations that may lend resources such as clipboards.
- A more cost effective and successful service can be developed if the people who will use the service are consulted, e.g. the community centre is now busy, whereas if it had been opened offering other facilities it might not have been as popular.
- Money is a good motivator – several of the local researchers only initially became involved for the money, but later became interested in the project for what it was.

Case Study 4: Preston Road Estate Community Project

Local people carried out a participatory appraisal of the estate to find out what residents felt needed changing in order to improve quality of life. They had complete *Ownership* of the project.

Key lessons learned:

About participatory appraisal –

- PA is relaxed and there is no pressure on people to respond in any particular way...so...

- people who wouldn't usually speak up, get a chance to
and
- information is gathered through natural interaction.
- When using PA, the researcher takes a step back and works more as facilitator than researcher.

About involving lay people in research –

- ***It is important to use flexible methods so that people of all abilities can be involved***
- ***Red tape and bureaucracy can be a problem when working with certain groups or getting permission to work outside properties, e.g. shops.***

Case Study 5: Holderness Youth Initiatives

Young people investigated a number of issues relevant to them in their community. The young people had *Ownership* of all projects, although a development worker supported them.

Key lessons learned:

- PA can be used with all age groups/sectors of the population
- Young people can make a difference to policy decisions by carrying out their own research
- ***Engaging with young people is not easy – the research (or conversation) must be fun and have some meaning to them, otherwise they will be easily distracted or not even become engaged in the first place***
- It may be hard to get support from the local community for initiatives to be followed up.

Case Study 6: Totnes Traffic Appraisal

A working group of local people formed to work towards solutions to the local traffic problems. With the support of the local council, they hired a facilitator to run public meetings and discussion groups in order to learn about all the different stakeholder groups' ideas and opinions. Local people had *Ownership* of the project.

Key lessons learned:

- It is not always possible to obtain all the funding necessary for a project's completion or unexpected expenses may occur.
- Research can be a long process. Local people often want fast solutions, but proposals put forward to the council may not be considered for months or years.
- It helps if people in the group are committed and willing to work together, working towards a solution rather than arguing over the various issues. It was important to keep politics out of the discussion and remain focused on the objectives.
- Sometimes it is necessary for people to use their own homes and equipment and to do work in their own time, in order to keep the project going, especially if there is limited funding.
- It is helpful if there is commitment from local authorities to co-operate with the group and to realise the longer-term outcomes.

Case Study 7: Barriers to Independence

Older people were recruited to advise research about barriers to independence for people over 55. They have become more involved than originally planned and intend to carry out data collection and analysis and have input on the way the results are implemented. This is an example of *Active* participation.

Key lessons learned:

- It is important to recruit a good cross-section of the target population, so that an enthusiastic group results.
- ***It is important to understand that allowing extra time is necessary when involving lay people.***
- ***Access to information is very difficult if you are not a member of a professional institution. The group has had to rely on colleagues in Social Services to get access to electronic databases. The research assistant was able to join the university library because she happened to also be studying part-time.***
- Access to software packages for analysing data is also a problem for groups not affiliated to a professional institution.
- Confidence building is an important part of preparation for lay researchers.

Case Study 8: Alternative Choices

Members of a mental health consortium investigated the alternative coping strategies used by local people facing mental distress. Lay people had complete *Ownership* of the project.

Key lessons learned:

- Research can be hard work for lay researchers who had to work from home.
- It can be difficult for lay researchers to find time to complete a project run voluntarily, e.g. writing up the report once employed in a new job.
- It is important that mutual learning occurs, that the giving of information is not just one way.
- Advertising in real terms, using language that includes rather than alienates, helps to engage people.
- ***It is helpful if a strong network of interested people already***

exists within the geographical area, so that there is commitment to the project. For the same reason, it is important to take the time to build relationships and make contacts within the area so that all the relevant people can become involved.

- The importance of working to realistic proposals and aims, i.e. not taking on too much in too short a time.
- ***It is important that lay researchers work with/alongside professionals, so as not to be perceived as a threat by them. Hopefully, professionals will then be willing to accept/learn from the information about alternatives that is suggested.***

In conclusion...

The major benefits of visiting the case study projects and meeting with the people involved were that it was possible to learn about all the aspects that are usually left out of a written report. For example, we could ask exactly when people had become involved and find out how much control they felt they had really had over the process. It also meant that we could learn about the circumstances behind the research and whether there were any common factors amongst these eight projects that made them work. Many of the lessons learned from the case studies highlight issues also drawn from the literature we have gathered. Some, however, we would not have come across without these personal visits.

The key lessons that came up from more than one of the case studies are outlined below:

- *It is important to have a supportive funding body that is willing to be flexible and open to changes in the research proposal as the project evolves.*
- *It is important to have an understanding and enthusiastic support worker/researcher working with lay people, to provide encouragement and any necessary guidance/advice.*
- *People are often more open and willing to talk to others who have had similar experience, e.g. mental service users talking to mental health service users.*
- *Research designs (and researchers) should be flexible in accommodating lay people's needs and constraints in order to maximise the opportunities for participation. It is important to consider factors influencing participation for a particular group of people, e.g. side effects of medication and fluctuations in mental health symptoms. People with learning difficulties, children and older people may have other needs that should be considered.*
- *Trying to recruit people from ethnic minority groups can be problematic. Different communities may have different research priorities.*

4. Helpful hints for lay involvement in research



Included in this section:

- ◆ Suggestions about *how* to
 - make sure that all the relevant people are involved;
 - encourage lay people to become involved in research;
 - work towards sustainable outcomes;
 - involve lay people in all types of research.
- ◆ Research techniques – a range of research techniques are considered.
- ◆ Can participatory research be rigorous?
- ◆ Tools for self-reflection, monitoring and evaluating lay involvement in research.

Among the questions often asked by professionals who seek to involve lay people are:

- 'how can we be sure that we ask all the right people to participate?'
- 'how can we get people interested?'
- 'how can we act on the findings of the research in a way that produces sustainable benefits for lay people?'
- 'is participatory research always appropriate, even in a scientific study?'

The tips outlined in this chapter are not intended to be definitive or exhaustive answers to these questions, but rather an attempt to provide solutions and make some suggestions based on approaches that are not commonly used in health research in the UK, but may be readily transferable.

The bit before the beginning

Before the start of a research project, it is important to identify who needs to be involved. A systematic approach has been developed to assess different dimensions of a project's impact on people and their environments. Called 'stakeholder analysis', this approach is being used in overseas development, and involves the identification of *"all those groups and individuals who have a stake, or vested interest, in determining the success or failure of an activity."*⁴⁶

Stakeholder analysis is a wide-ranging activity that helps planners to identify a variety of different groups of people that may be affected by the project, or highlight those which may have been overlooked. One dimension of this analysis involves looking at the social relations between the different stakeholders. The process involves exploring the interests, the potential impact of the project and the relative priority of interests of different stakeholders, from the perspectives of all those groups involved. Checklists of questions for stakeholder analysis have been devised^{46 67} which ask about expectations of the project, potential benefits and drawbacks, resources, conflicting interests, and how stakeholders view each other. For guidance on how to undertake a stakeholder analysis, see DFID's website, www.dfid.gov.uk/public/what/advisory/group7/pdf/sddstak1.pdf.

Engaging with people

In the projects we identified, a variety of means were used to recruit lay people. Often, approaches were made through voluntary organisations or user groups that represented a particular interest.¹⁹¹ Media advertising and posters put up in appropriate places complement other methods of reaching potential participants.^{19 55 95 117}

¹⁶⁷ Groups of people such as elderly people or people with disabilities

Extract 1

“Establishing a contact group – the first six weeks was taken up with establishing a group of local people who could act as the focus of the research. It was important that [they] should be drawn from across the community. Statistical data and local knowledge confirmed that the area was made up of [at least] three distinct geographical areas, one of which contained a significant Asian population.”

may be targeted and recruited by using agency records, medical records or official statistical information to establish a contact group (see extract 1¹⁶⁷).

Some reports highlighted that lay people had been identified because they were thought to be ‘key informants’,¹¹⁷ or by using a ‘snowballing’ process,⁶² where prospective participants were identified by other recruits. Some had been ‘co-opted’ or had volunteered,¹⁹¹ and some identified by statistically representative sampling.⁴⁰ In one overseas setting, all villagers were present at an initial meeting.⁷²

Wilcox’s Participation Guide²¹³ refers to a number of ways of engaging lay people. We have already mentioned that research needs to grab people’s interest. Of equal importance is building relationships and being open in communications and available to participants.

One way of engaging lay people in identifying issues and problems to investigate, is participatory appraisal (PA). PA developed as a method of empowering lay people to investigate their own needs and possible solutions, and has been widely used in overseas developmental projects. In recent years, it has been used in many settings in the UK: community development, regeneration and public health.^{55 92} It has the advantage of being a fairly quick method of appraising community needs, using local knowledge about issues and problems. Lay people control the level of their participation and take an active part. Participation usually takes place in familiar settings such as the street or community centres.

Case Study 4	Field: Community Development (UK) Group: Local people
<p>On the Preston Road Estate in Hull a group of local people were trained in participatory appraisal methods to investigate problems on the estate and what needed changing for the quality of life to improve. They then went out to other parts of the estate and engaged with community members. The local researchers found that it was a relaxed and flexible way of working that enabled people who don't usually get a chance to speak, to do so on their own terms and in their own settings. It was possible to include all ability groups in this way, as people did not feel under pressure to respond.¹⁰⁵</p>	

With the aims of sharing knowledge and mutual learning, PA can be the start of an active process, which leads to positive change and inspires people to continue with research. This approach employs a wide variety of participatory tools, mostly visual ones, which do not rely on literacy skills. Some of these are considered later in this chapter. Tock¹⁸⁹ (and see extract 2⁵⁵p22) highlights the importance of process over method, but does emphasise that other methods may be needed to complement this approach.

Extract 2

“The quality of the data is not the primary consideration in participatory research: what matters far more is the extent to which local people have become involved in the process.”

Sustainability

Sustainability has been identified as an important factor in service delivery, development and research. So many short-term projects bring improvements to people's lives for a short time, then when the funding runs out, the project folds. Thus, particularly in community development and regeneration, the concept of sustainability is becoming an important feature. But how can this be achieved?

A holistic approach to researching with communities has been developed and is now being used a lot in overseas development. This is called the sustainable livelihoods approach (SLA). The approach is people-centred and defines success in terms of the achievement of benefits that people define themselves. The affected community itself is the key to the process, so must actively participate in the research. Outcomes must be sustainable and make a lasting contribution to the community. The approach is multi-sectoral, recognising that there are links between all agencies and sectors in people's everyday lives. DFID, as well as other agencies (e.g. CARE, Oxfam), is now using this approach. For more information, see the DFID guidelines.^{9 68}

<p>Example from the literature: Ward (2000)²⁰⁵</p>	<p>Field: Overseas Development Group: Local women</p>
<p>The Wet Season Losses Project in India used participatory research methods to identify a range of coping strategies which poor women from a number of villages were using to address losses of fish during the monsoon period. This season provides gluts of fish but the weather conditions hamper drying which can lead to substantial loss of money and, in some cases, suicide. It was found that some women had developed strategies, but no group of women had a comprehensive suite of strategies to cope with a diversity of problems. The research amalgamated tactics from different groups. These were then presented to the women, who selected a group of strategies that they thought might work in their situation, modified them to fit in with their working practices and then tested them.</p> <p>In the main, the new approaches were taken up and used by the women. The level of uptake was used as an indicator of acceptability of the research outputs.</p>	

SLA is a philosophy that links in very well with participatory research approaches. Community-based processes focus on solving problems and creating positive change. In health, we might use the term

'sustainable well-being' defined as promoting a good quality of life.⁴² The development of 'coping strategies' provides a good example of how this may be achieved.

Is participatory research always appropriate, even in scientific studies?

We consider two questions here. Firstly, is it appropriate to involve all groups of people in participatory research?

Involving children and people with learning difficulties in research is sometimes avoided by professionals on the grounds that they may either not understand the process, or may be exploited by it. Some professionals try to adopt a participatory approach in relative straightforward cases only (excluding children, people with learning difficulties and people with mental health problems).³⁶

Despite the concerns of some professionals, there are some excellent examples from the field of social care of studies that have actively involved those groups of people mentioned above. With care, sensitivity, adequate planning and excellent facilitation, there appear to be few problems that cannot be overcome.^{6 91 139 170 209 211 216 217}

There may be some disadvantages to the use of peers as researchers when sensitive information is being exchanged. Some respondents might not wish to 'open up' to their peers, and peer researchers might fear getting too close.^{37 177} One way of getting over this problem was employed in a study of mental health service users, where interview respondents were given the choice of being interviewed by a professional researcher or a peer interviewer.¹⁷

<p>Example from the literature: Rose (2000)¹⁷⁰</p>	<p>Field: Social Care/Health Group: Mental health service users</p>
<p>A recent national study of mental health service users' views, undertaken by the Sainsbury Centre for Mental Health, not only involved service users in the design of questionnaires, but offered training in interviewing, so that the survey was conducted by the users themselves. They were successful in gathering data from other users because the respondents felt the interviewers understood their needs.</p>	

The second question is can lay people become involved in scientific research?

We discovered that in the field of overseas development, farming (and fisheries) scientists and lay people often work together towards technological solutions to problems. We refer particularly to on-farm client-oriented research (OFCOR),²⁵ one of the ways in which collaborative scientific research can be undertaken.

OFCOR involves continuous interaction between researchers and farmers, who are seen as partners in the research process. The emphasis is on treating farmer participation as a 'monitoring' function to help plan the on-farm and on-station research each year. Diagnosis and assessment are carried out continuously with farmers and are not seen as activities that occur only at the beginning and end of a project. For example, farmers are asked at the start for advice on whether they have already investigated a given problem or tried a certain technology. They are also asked how they would go about testing, for example, a new crop variety. An illustration comes from Zimbabwe where the Farming Systems Research Unit programme, after suggestions from farmers, changed a randomised block design

for a crop trial to a strip design because it made it easier for farmers and researchers to compare treatments.

The process is flexible. Each year, a range of surveys, trials and management methods is used. Priorities in the use of scientists' time and other resources have changed from an emphasis on collecting formal data to holding meetings for different purposes, involving different groups of farmers and other people at village level. For more information about the OFCOR approach, see Biggs.²⁵

Research Techniques

“One consequence of the evolution of participatory methods has been the discovery of alternatives to the normal applications of questionnaire surveys.”⁴²

One of the themes that has emerged from our review of the literature is that research should be enjoyable. Having ‘fun’ was an essential part of the process in many of our case study projects, especially for young people. But for other groups as well, enjoyment, feeling that they could make a real contribution, and being able to understand the process were key features in making the decision to become involved in research.

The majority of the studies we looked at involved traditional questionnaire surveys and interviews. However, there were considerable differences in the ways in which these were designed and administered. Sometimes the questionnaire would come out of an extended process of negotiation, and would be designed by lay people in conjunction with professionals. A few studies employed group discussions, often in addition to surveys.

We outline a variety of techniques below, which may be more or less appropriate at different stages of the research process. We were

Extract 3

“Visualisation offers a powerful strategy for working with those whose voices are rarely heard, as well as for bringing about critical awareness and self-confidence among participants in the process.”

particularly interested in those techniques that can be used to engage lay people’s interest at the start of a project, where more traditional methods might have been used at later stages. For example, ‘Community Visioning’ may be a good way of enabling people to create a picture of their communities (see extract 3⁵⁴p96), so could provide a starting point. Other methods may be more valuable as the process continues.

We put forward examples of less commonly used methods, from our reading, which may complement the more traditional. We have not intended to provide a toolkit, but felt it important to provide some descriptive examples. We refer readers to several publications which provide more detail: Developing Focus Group Research,¹³ Whose Reality Counts?⁴² Participatory Learning and Action: A Trainer's Guide,¹⁶¹ Participation Works!,¹⁴³ Conducting A Participatory Evaluation,¹⁹⁹ Prove It!,²⁰³ and Evaluating Sexual Health Services: 'How to do it'.²¹²

Research tools have three characteristics. They may be:

Visual

Oral and/or

Written

Different techniques are used in combination, often at different stages in the research process. Whereas, for example, mapping often occurs at the start of a project, video techniques may be more likely to be used as a form of data collection.

Visual techniques are a vivid way of seeing a problem quickly and powerfully (see extract 4⁴²). They also offer a way of overcoming differences in language and knowledge that often act as barriers between groups. There was only one passing reference in the literature to some visual techniques being ‘patronising’ to adults.⁵⁵ In general, they were found to be enjoyable as well as insightful, and

Extract 4

“I was amazed to see the professional expertise with which this illiterate man used seeds and chinks. I was also impressed with the wealth of information and how he was enjoying telling people his history. I got many answers to my questions from that one day in the field.”

have been used by a variety of groups, but children have found them particularly valuable.¹¹¹

Videos: give an excellent perspective of life from the point of view of some lay people. This technique has been used effectively with street children in Nepal,¹¹ and homeless people in the UK.²²⁴

Example from the literature: Akilu (1995) ⁵	Field: Housing Group: Homeless young people
A group of young people approached a researcher in Reading because they wanted to make a video that could be used in schools to inform young people about homelessness. Using other homeless people as a reference group, they designed a documentary type interview about the experience of homelessness. The film they created has been shown in schools and clubs in the area, vividly describing the unpleasantness of the homelessness experience.	

Pictures: It is not only children who can benefit from drawing pictures. This technique has been used successfully with a number of groups. For example, drawing a 'problem wall' and a 'solution tree' is an enjoyable way of visualising difficulties and identifying potential solutions by a group of participants.⁵⁶

Mapping: asking participants to draw a map of the area in which they live is an excellent way to help project workers to become familiar with an area, and to gain understanding of how people see their neighbourhood and identify issues of importance to the community. Gender, age, well being and occupation will affect what people put on their maps, and the way and order in which they draw things.²¹²

Timeline: this is a tool for showing significant or important events in a community over a period of time. Different people will have different perceptions about the importance of changes.

Time clock: this tool was used by young people in the UK, to show the times of day when they would be able to use a sexual health service.²¹² They drew a clock face, divided it into twelve segments, and indicated the times when they would be able to access such a service.

Priority ranking exercises: this is a visual technique in which people list their priorities and then pair them off, two at a time, until the most important issues emerge at the top of the list.¹⁶¹

Participatory theatre: this technique uses physical movement and creativity to explore people's experiences. This also overlaps with oral techniques.¹⁴³

Example from the literature: Johnson et al (1998) ¹¹¹	Field: Overseas Public Health Group: Local people
In a study in East Africa investigating sexual behaviour, groups of participants developed messages to be promoted within the community using traditional means, with storytelling by elders, and with dance and drama performance by children and young people.	

Oral techniques include the more traditional structured, semi-structured and in-depth interviews, as well as focus groups and other kinds of group discussion.

Focus groups: are group discussions exploring a specific set of issues. The group is focused in that it involves discussion around areas of common concern. The interaction of group members generates data. Focus groups are facilitated and observed. They differ from group interviews because members of focus groups ask each other questions and exchange information. They also differ from 'brainstorming' sessions that are unstructured.

Telling of stories: Stories capture the essence of what matters to people. Through this process, participants may relate their experiences of a problem in a powerful and personal way.

Written techniques include the traditional survey questionnaire method, but also writing stories and diaries of events and feelings.

Research diaries: can be used by researchers as part of a reflective process during the research, or can be used by participants to document important events or episodes that are relevant to the research process. Such reflective passages can be powerful tools in expressing the experience of a disease, or bullying at school, for example.

Example from the literature: Mellor (1998) ¹³⁷	Field: Education Group: Teachers
<p>Nigel Mellor describes how he kept a research diary over a period of two years while he was incubating ideas for a research project. The reflections written in his journal helped him to understand the direction in which the changes in his philosophy were taking him as far as research methods were concerned.</p> <p><i>“It was only later [in the process] that I realised that my diary was my research tool, not just a companion. It became a systematic way of managing the confused space I had entered.”</i></p>	

Visualisation: this technique should be expertly guided. It involves people creating a vision of their community (or healthcare) in a positive way for the future. Visions are written on post-it notes and displayed so that all participants can see areas of consensus.¹⁴³

Can participatory research be rigorous?

“In the varied topography of professional practice, there is a high, hard ground overlooking a swamp. On the high ground, manageable problems lend themselves to solution through the application of research-based theory and technique. In the swampy lowland, messy, confusing problems defy technical solution. The irony of this situation is that the problems of the high ground tend to be relatively unimportant to individuals or society at large, however great their technical interest may be, while in the swamp lie the problems of greatest human concern. The practitioner must choose. Shall he (sic) remain on the high ground where we can solve relatively unimportant problems according to prevailing standards of rigor, or shall he descend to the swamp of important problems and nonrigorous inquiry?”¹⁷⁴

Different types of research can be evaluated in different ways. In traditional, science-based quantitative research, values of objectivity, validity, reliability and generalisability are emphasised. The researcher must not get personally involved, must somehow stand back from the process and remain outside (*objectivity*). The research should measure what it is intended to measure (*validity*), it must produce similar results if repeated over time (*reliability*) and it must be *generalisable* from the sample being studied to other similar populations. Therefore the sample should be large enough for results to be ‘statistically significant.’

In qualitative research, transparency, trustworthiness and transferability are emphasised. Qualitative researchers believe that nobody can be totally objective and neutral, and bias is minimised by

acknowledging researchers' perspectives and by being open about all aspects of the research process (*transparency*). The methods for gathering and analysing information should be *trustworthy*. Enough should be known about the sample being studied to help in judging the extent to which the findings are applicable elsewhere (*transferability*).

Taken together, all these considerations help to ensure that research is rigorous. Participatory research should be no less rigorous and will need to meet additional criteria to ensure that it is of high quality. Participatory research should be relevant and seek findings that may be applicable in the real world. For example, in overseas development, adoption by farmers of the findings of a study demonstrates its value.^{125 133}

Often, participatory research deals with small 'samples.' Although perhaps not 'statistically significant,' findings from small samples can be crosschecked with evidence from other studies. The difficulty in doing this may lie in the way in which small studies are reported and how widely findings are disseminated. The World Bank Poverty Voices project is a good example of how findings can be amalgamated.^{221 101} 'Triangulation' is also an important way of validating research. In brief, this refers to the testing of conclusions by using a number of different methods, involving different researchers and confirming the trustworthiness of results by feeding back to the community.

Pretty¹⁶⁰ has posed four questions that participatory researchers should try to answer in order to persuade their audience that the findings of a study are worth taking account of. These have been adapted by us and reproduced here:

- How can we establish confidence in the findings?
- How applicable are these findings in other contexts or with other participants?

- Would the findings be repeated if the research was replicated with the same (or similar) participants in the same or similar contexts?
- How can we establish whether the participants and context of the research, rather than the biases, motivations and perspectives of the researchers have determined the findings?

Below, we consider ways in which some of these questions can be approached systematically, with the use of tables and matrices assessing the type, quality and quantity of participation as well as monitoring the level of participation throughout the research process. Using tables and matrices may not suit everyone, so these are offered merely as suggestions.



Tools for self-reflection, evaluating and monitoring the process of participation in research

1. Framework for analysing the balance of participation in research

Table 4 (overleaf) describes a number of potential types of participation along a continuum from professional-led to lay-led research. Under each type is a list of characteristics and examples of investigations where these types might occur in health research.

For the purposes of this study, we only considered research projects that fell between types D to I, as those were the categories where lay people could have an active influence on the research process.

Table 4: A Single Dimension Framework for Analysis of the Balance of Participation in Health Research

(Adapted from Campbell & Salagrama³⁹)

Type of participation in the research process								
Professional researcher-led				Lay researcher-led				
TYPE A	TYPE B	TYPE C	TYPE D	TYPE E	TYPE F	TYPE G	TYPE H	TYPE I
Professional exclusive	Professional-led contract	Professional-led consultative	Professional-led collaborative	Collegial	Lay-led collaborative	Lay-led consultative	Lay-led contract	Lay Exclusive
Characteristics of each type of Participation								
Only involvement of professional research participants	Professionals 'buy in' the skills and knowledge of lay people	Professionals utilise knowledge of lay people for their own purposes	Professionals allowing the involvement of lay people in the research activities of the professional under prescribed conditions	Professional and community researchers work equally together to generate knowledge on a constraint of mutual importance	Lay people allowing the involvement of professionals in the research activities of the community under prescribed conditions	Lay people utilise the knowledge base of the professional researchers for their own purposes	Lay people 'buy in' research support from outside to address their needs	Only involvement of community-based research participants
An example of investigation where these types might occur in health research								
Research which is remote from the community. For example that which is carried out in the laboratory	Lay people are paid to take part in research activity in some way, perhaps as 'subjects'	Professionals interview lay people to access their knowledge concerning the problem or sample lay people using a survey questionnaire	Professional researchers work with lay people to draw up and jointly execute a project using methods defined by professionals	Lay people and professional researchers share a common need to identify new resources, they work together to develop a methodology, implement the research together sharing their knowledge and skills, analyse the data jointly and share in ultimate dissemination and use.	Lay people request assistance from a research institute to address a particular need they have. They work with the professionals to draw up a project using methods defined by lay people.	Lay people consult professional researchers on their knowledge about the problem or need which has been generated elsewhere	Lay people request support from a formal research agency to address a specific issue.	Lay people generate lay knowledge of the problem through their own methods of observation and validation.

2. Monitoring participation during the process

The table below outlines stages in the research process and levels of participation. It can be a useful guide to researchers in assessing and monitoring lay involvement in research. We have chosen this because it is easy to use and can give a clear picture of the level of participation at different stages of a project.

One of our case study examples, the Barrow Community Gym Project¹⁹⁶ has been applied to the model below as an example. The process started as an academic-led evaluation of the services, but quickly evolved into a partnership and eventually resulted in gym users taking ownership of the project so as to continue with a six-monthly evaluation of the expanding gym.

Table 5: Participation at different stages of the project cycle
(adapted from Empowering People⁴⁶)

Project Cycle	Type of Participation*			
	Passive	Consultative	Active	Ownership
Problem identification	✓			
Project design			✓	
Planning			✓	
Data collection				✓
Analysis				✓
Writing up		✓		
Dissemination			✓	
Action and evaluation			✓ (evaluation of project by academics)	✓ (gym users took on ongoing evaluation)

*See chapter 3 for explanation of typology

3. Assessing the quality of participation

The matrix overleaf (Table 6) gives tips to researchers on questions to ask about the quality of participation in research. It raises some key questions about aspects of participatory research that may not always be evident, for example how the language is framed, how different knowledge systems are accommodated, who controls the research and who benefits.

4. Table for assessing the quantity of participation

Table 7 takes the features of research outlined in the matrix described above and looks at the quantity of participation on each feature from the perspective of the lay participants. We have applied this table to one of our case studies in order to exemplify how it can be useful to researchers and lay people.

5. Identifying issues as a guide to methods

According to Wilcox,²¹³ *“the problems in participation processes seem to relate to about 15 underlying issues. If you can spot the issue, by asking the right questions, you may be able to find a participation method to use”*. We note below the issues that he has identified:

People

- ◆ Roles: who plays which roles in the process and what responsibilities do we each have?
- ◆ Communication: are we talking the same language and do we understand each other?
- ◆ Negotiation: how can we reach agreement?
- ◆ Increasing commitment: how can we get people to play an active part: Why are people not interested, and are my colleagues with me?

Table 6: Quality of Participation Matrix³⁸

Feature	Description	Range	Example of good practice
Relative balance of involvement of the different participants in the research	The extent to which lay people are actively involved in the research process at different stages	Contractual – consultative – collaborative – collegial	Lay people participate on an equal footing with researchers
Control	The extent to which lay people are actively involved in the decision-making about the research process at different stages	Consultation – choice of options – selection of options – decide on the selection process	Lay people, jointly with the researcher, make all decisions concerning the research
Stage of the process	The stage(s) in the research process at which the lay people are involved	Problem identification – priority setting – funding allocation – selection of research partners – research design – methods – implementation – analysis – interpretation – dissemination – use	Lay people participate in the research at all stages from problem identification through to dissemination and uptake
The quality of participation	How does that participation manifest itself?	Transparency – access to information – decision making – accountability – comprehensiveness – non-alienation	The lay people define the qualities of participation that are important to them and the standards to be achieved. The research process is then scored not only in terms of its results but the quality of the participation as well
Language	The extent to which the research is framed in the language used by the researcher or that of the user. This could be at the extreme of English researchers working within a Bengali community in an inner city, or it may be just the difference in the level of technical terminology used	Language of the researcher – mixture – oscillation between the two – language of the lay person	The principal language of the research is that of the lay person and the terminology used is that which the lay person is most familiar with
Frame of reference used	The extent to which the different knowledge systems of the researcher and lay people are used as the framework for the research	Value/knowledge system of the researcher – mixed – value/knowledge system of the lay people	The frame(s) of reference of the lay people is/are defined in advance of the research and the research is implemented within that framework but with bridges across to that of the researcher
Benefits	The type and level of benefits that accrue to the individuals and groups (researchers and lay people) involved in the research	Awareness raising – increased knowledge – increased skills – changed attitudes – direct effects – immediate positive impacts – longer-term positive impacts	The lay people leave the research with clear and distinct benefits which they define as important
Empowerment	The extent and form of empowerment that the participation enhances in the lay people. In most cases this will be something which builds on control (see above) which is mainly an internal attribute, to become something which extends after the research	No empowerment – shared power – lay peoples' empowerment after the research is significantly enhanced	The position of power of the lay person with respect to his/her help and to the health service is enhanced in a way that is sustainable after the research is completed.

Table 7: Quantity of Participation Table³⁸

Feature of participation	Scale	Low	Medium	High
Relative balance of involvement of the different participants in the research	The degree to which lay participants perceive they are involved in the research			✓
Control	The level of control the lay participants feel they are able to exert during the research			✓
Stage of the process	The number of different stages they consider that they meaningfully participate in			✓
The quality of participation	Their perception of the level of quality of their participation		✓	
Language	The extent to which the lay participants consider that the language of the research reflects that used by themselves			✓
Frame of reference used	The extent to which lay participants consider that the frame of reference used in the research reflects their own			✓
Benefits	The extent to which the lay participants derive clear and immediate benefits, as defined by themselves, from the research process		✓	
Empowerment	The extent to which the lay participants consider that the participation in the research has given them lasting empowerment after their involvement in the research	Not yet known		

The example above comes from our case study, Bournemouth Help and Care (see Annexe F)

Process

- ◆ Taking stock – situation assessment: identifying stakeholders, barriers to action and who holds the power
- ◆ Taking stock – self-assessment: what can we achieve and how confident are we?
- ◆ Developing criteria: agreement on priorities and values and choosing between different options
- ◆ Clarifying purpose, values and vision: what are we trying to achieve and how will it feel if we succeed?
- ◆ Managing structure: how will we do it?
- ◆ Making decisions: how can we choose between different options and what to do next?
- ◆ Generating options: how can we think creatively to produce a number of options?
- ◆ Evaluating progress: how will we judge whether we are succeeding or not?

Resources

- ◆ Getting resources: what money, advice and other resources will we need?
- ◆ Developing skills/capacities: how will we develop the ability to work with others and achieve what we want?
- ◆ Developing structure: what type of organisation may we need – either in the short term to make decisions or in the longer term to carry out plans?

For each of the above items, there is a section in the guide that helps would-be researchers to find the answers. The guide is available on the Internet on www.partnerships.org.uk/guide.

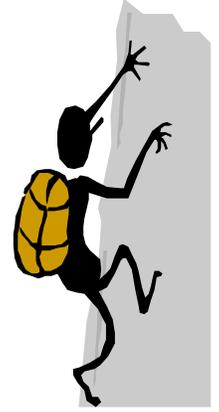
5. Factors that help or hinder lay involvement in research

Included in this section:

- ◆ The literature searches revealed a number of factors that acted as barriers to, or facilitated the process of participatory research.

These are categorised under the headings:

- People (their attitudes, diversity and values)
- Process (knowledge and power)
- Resources (time, money and support)



“..in conventional research one would not expect to involve the study’s participants in shaping the research question. However, convention does not always provide examples of ‘best practice’... since it is participants who have the greatest wealth of subjective knowledge of their own experiences...”²⁰⁷

The barriers and facilitating factors noted below come from a variety of sources from the fields of public health, health education, social care, housing, community development, education and overseas development. The projects involved young people, older people, people with mental health problems, people who had learning difficulties and more generic groups of lay people in geographical communities. Some of the background material included involvement in shaping services as well as in the research process. There was considerable agreement about factors for effective involvement or participation.

Barriers

We have looked at the experiences of many researchers who have highlighted some of these barriers in fields outside health research. We have categorised these below, giving examples.

People:

Attitudes

- Professionals fear that involving lay people in research will lead to increasing demands from lay people.¹⁸⁰
- When professionals ask communities to define their own problems and needs, they are often surprised by the results but may have difficulty in accepting community views as valid. Lay recommendations may make agencies defensive.³⁷
- If lay people are researchers, there may be difficulties in gathering information from professionals, who may show resistance.²⁰⁹
- People who are socially excluded or marginalised may be suspicious about professional motivation, or cynical about being involved in 'yet another project'.⁶⁹ In turn, professionals may not trust the results of community-led research (see extract 5¹⁶⁷).
- Professionals create the impression that lay involvement is not important, for example, by not building sufficient costs into the budget to conduct participatory research.⁴⁸
- Professionals assume that research that actively involves lay people lacks rigour and reliability.⁵³
- **Professionals assume that participating communities are 'born' rather than 'made,' and require no effort to engage.**⁵³
The literature indicates that people will not become committed if they feel they cannot achieve anything¹¹³ and when research is not seen as relevant to the community.²¹
- The superior attitude of some professionals is belittling and disempowering.¹³⁸
- Professionals are often unwilling to share specialist knowledge.¹⁸⁰

Extract 5

"...many barriers [to community-led research] still remain. The most difficult to overcome are those associated with the commissioners of research – namely their organisational inability to handle input from the community, and their reluctance to 'trust' the community to produce valid and relevant results."

- Professional priorities may overlook users' experiences and understanding, resulting in services that fail to meet people's needs.¹²⁸
- Statutory sector staff often lack the communication and facilitation skills necessary for community participation to work. It is common for the statutory sector to impose its own management structure onto community partnerships, expecting community members to adapt to existing practices, rather than working co-operatively.⁴⁸
- The absence of a strategy which purposefully guides the promotion of participation in a project shows a lack of commitment to involvement¹⁰³¹ (see extract 6⁴⁶).

Diversity

- Professionals may assume that lay people form homogenous groups, and they therefore oversimplify lay issues. This overlooks the diversity within groups and differences between them. Issues that arise, for example, because of gender, ethnicity and disability can be ignored if only the 'dominant' perspective is considered.¹⁰³
195 181
- It is difficult to identify who should consult with whom about what. The array of different organisations which exist to purchase, provide and support public services is confusing (see extract 7¹³⁰p31).
- In the case of some groups, attendance at a stakeholders' meeting might not be possible or appropriate.⁵² If some of the stakeholders are ill or disabled, or if they belong to groups of people who find it difficult to communicate because they feel powerless (e.g. children and some people with learning difficulties), other means of involvement are necessary.
- ***There is a view that articulate lay people are not 'typical' and do not reflect the views of all lay people.***³¹
- Voluntary groups are often seen as being the route to lay representation, but they are 'not neutral' and often have their own agendas^{109 113 20}(see extract 8¹⁸⁰).

Extract 6

"A major reason why people's participation is not consistent or effective in many projects is because time and resources have not been given to thinking through how it is promoted."

Extract 7

The fragmented state:

"The result of the increased privatisation and decentralisation of the state services that occurred in the UK during the 1980's and 1990's has been the emergence of a growing number of agencies operating somewhere between central and local state and between public and private spheres. These 'intermediate' bodies comprise a range of different types of organisations with a variety of functions. Their categorisation is not assisted by the changing terminology of political analysts and/or, some would argue, a policy of deliberate confusion on the part of central government."

Extract 8

"Statutory sector staff have expressed concerns over 'representativeness'. They have questioned the extent to which community groups can be seen as representative of society at large and whether special interest groups are truly representative of all individuals with a particular interest."

- The supposed difficulty of finding representative lay people is sometimes used as an excuse to avoid asking people to participate at all.²³
- Participatory research requires professionals from different disciplines to work together. They may not always be willing or able to do so.⁴²

Values

- Some professionals fail to recognise and provide for the special needs of some groups. For example, extra consideration is necessary in relation to gaining informed consent when working with children or people with learning difficulties.^{6 181}
- Lay people may be led to believe that their participation can lead to certain outcomes. When these expectations cannot be met, this can be disempowering^{31 138} (see extract 9⁵³).
- Insensitive handling of distressing disclosures raises ethical concerns noted in the field of social care.³⁷
- Conflict and misunderstanding may indicate evidence of lack of honesty and trust in the research relationship.¹⁸⁰
- What happens to people at the end of a project is often overlooked, for example lonely people may expect continuing friendship.^{27 117 146 181 192}
- Putting research out for tender raises questions about whether work of reasonable quality can be completed without exploitation of the researchers and participants (see extract 10⁶p33).
- Some communities become ‘over-researched’ with little crossover of information between agencies, leading to the same questions being asked again and again, often with no feedback to the participating communities.^{36 150 115}

Extract 9

“Practitioners need to tread a careful path between generating sufficient interest for participation and not raising false hopes.”

Extract 10

“In practice, subjects are at the bottom of the pile – no pay, or formal protection or recognition, and at risk of ‘grab-and-run’ data collectors, especially when these researchers have too little time and support.”

Process:

Knowledge

- Lay people may lack knowledge in many areas: what 'research' actually is, how to access information (which is often available only on academic databases), how to seek funding for projects, and how to gather and analyse data. They may also lack the necessary organising experience. Lay people may be put off becoming involved if the research appears too theoretical. The need for training lay people in these areas is often overlooked.^{10 76}
202 206
- Professionals may lack vital local knowledge that contributes to the identification and solution of local problems.^{10 53 180}
- Professionals may not know who to involve.^{10 53 168 180}
- The use of inappropriate language excludes some groups of lay people (extract 11¹⁸¹).
- Lack of appropriate or sensitive communication skills with some groups of lay people (for example, children and people with learning difficulties) by some professionals, hinders the research process and presents an issue for professional training.^{10 20 134 181}
- The assumption that professional ways of acquiring knowledge are superior to 'lay' methods can hinder partnership.²⁰²

Extract 11

“During one of the meetings some academics became involved in discussing methodological niceties which clearly excluded the two disabled members. However, the local authority officer later commented that he had been unable to follow this part of the discussion.”

Power

- Involving 'token' lay people in large groups of professionals without adequate support, is tantamount to non-involvement and often leaves these people marginalised in the group, as well as isolated from their peers^{20 31} (see extract 12²¹).
- If the policy implications of research are threatening to the funders, they may not wish to involve lay people in the research process.^{53 193 194 202}
- Commercial funders very often do not have lay members on their committees and are highly influenced by scientific research.¹⁰⁰

Extract 12

“A token consumer in a large group of professionals [is often there] to satisfy a ritual expected of them. Their only concern is to proceed as usual with as little disruption as possible.”

The focus of research therefore tends to be on commercial rather than community interests.

- Professionals may nominate lay people because they are likely to agree with a professional agenda.¹⁸¹
- Many efforts at involvement fail because professionals try to reach too many people 'at-a-stroke'.¹⁹⁷ One way in which this is often done is to arrange a public meeting, where the agenda is set by professionals and is inflexible, so marginalised groups cannot find a voice.¹¹³
- Lay people are unlikely to be powerful in setting the research agenda, unless funding agencies also take on a lay perspective, since a special set of conditions must be met to ensure effective lay involvement (see extract 13⁴⁶).¹⁷⁷
- Projects that are designed by professionals may not seem relevant to lay people and vice versa.²²
- Often too little consideration is given to the differing power relationships between researcher and researched, leading to manipulation of the research by the powerful according to the agency's priorities. 'Us' and 'them' attitudes that prevail can belittle and further disempower people.^{53 134 202}
- Sometimes professionals deliberately or unwittingly impede access to lay people to participate in research.¹⁸¹
- Previous experience by some lay people who have been users of services may affect their willingness to become involved in research, (extract 14³¹) as they may fear losing benefits or services in the future.
- Recruitment of lay people often does not take place early enough in the research process, so that lay people are not involved at the start of a project and do not 'own' the process. Control therefore rests with professionals.¹¹⁷
- The proportion of lay people to professionals on a research advisory group or steering group usually favours professionals, leaving lay people vulnerable.¹⁸¹

Extract 13

"It is critical that efforts to promote participatory development understand and examine the political and cultural context in which participation is to occur. Participation does not take place in a vacuum, but its development and progress will be influenced by a variety of factors inherent in the context. Time should be made available, therefore, at the beginning of any participatory project, to identify and to analyse the factors which could influence the process."

Extract 14

"Users felt staff didn't always understand the barriers created by their previous experience of powerful professionals... nor the power differences reinforced by their high level of dependency on staff at times of crisis."

- Ethics committees set up to protect, but not empower, participants discourage active lay involvement.¹⁰⁰

Case Study 3	Field: Community Development (UK) Group: Local people
Local people were recruited to carry out door-to-door surveys to get views about the potential usage of a new community centre, but they had little say in the content of the questionnaire and therefore found it difficult at first to ask someone else's questions. ¹⁷⁷	

Resources:

- A number of resources that should be provided are not often included at the planning stage, for example training lay people and professionals in each others' languages and meanings (extract 15¹⁸⁰). Training, when provided, is often classroom based with lectures, and not appropriate for some groups of people.^{37 43 113}
- Other resource issues that are often not addressed in the planning stage include the payment of lay people for their time, the provision of transport, accessible and non-threatening meeting places, crèche facilities or sitters, and payment of expenses^{20 192}(see extract 16²²).
- A number of projects pointed to constraints of time in participatory projects. In particular, time is needed, but often not available, at the start of a project to build up relationships with communities. The time allocated to projects doesn't reflect the complexity of participatory research.^{10 21 206 53 115}
- Lay people often want answers to questions *now* and may lose interest if the research process is lengthy.^{22 180 181}
- Some projects can wait in the 'pending' tray for ethics hearings for so long that the process is unnecessarily delayed.³⁶

Extract 15

“Working through the language barriers, resolving conflict and identifying common agendas is time consuming and labour intensive.”

Extract 16

“Time and money were great enemies of this project. Participatory research requires more of both than conventional approaches. Its commitment to the inclusion of all groups on equal terms has a number of cost implications; including the costs of accessible meeting places and transport; support for people to take part, including travelling expenses, interpretation, child care, personal assistance and respite care; and the provision of accessible information in appropriate formats..”

Extract 17

“As long as research funding remains primarily in the control of the scientific community, few participatory research studies are likely to be funded. This impression is supported by findings that many participatory researchers disguise their projects in ‘respectable quantitative clothes’ when seeking funding.”

- Given the complexity of communities, and the rapid pace of change within communities and the public sector, delays in securing funding for a project may render the research obsolete before it is complete.⁴²
- Lack of time is critically related to lack of funding. The additional money required to cover the costs of training, salaries and expenses for lay people, as well as professionals, is often overlooked in participatory projects.^{22 128 180 206}
- Many funding bodies are not flexible enough to respond to changes that occur during the research process.^{53 202}
- Competition for research funding is intense. Money is likely to go to the lowest bidder, which can mean that corners are cut and budgets insufficient. ***This often means that bidders for research funding have to omit references to the research being participatory*** (see extract 17²²).^{22 88}
- Support in a variety of forms is often lacking in attempts to involve lay people in research. Typically, lay representatives lack an advocate in the process¹⁸¹ or are not given basic equipment to undertake their work.³¹

Facilitating factors

The majority of facilitating factors are simply the other side of the ‘barriers’ coin. It is fair to say that our search of the literature revealed more barriers. We have not, therefore, reversed all of the barriers, but have included in ‘facilitating factors’ those suggestions for ‘good practice’ that have come out of researchers’ positive or negative experiences of participatory research.

People:

Attitudes

- Professionals need to be honest in identifying the limitations of what can be achieved at the outset of a project to avoid raising false hopes.⁵³
- Funding should be sought from those agencies that acknowledge and value participatory principles⁸⁸ (see extract 18²²⁶).
- Professionals should embrace the positive aspects of different methods of involving lay people.¹⁰³
- Changes in bureaucracies are required that will foster commitment to participation (see extract 19⁴³).
- Research into lay perspectives has been facilitated by those organisations that are committed to giving a voice to lay people and who are responsive and flexible in their approach to research, e.g. The Joseph Rowntree Foundation.¹¹⁸
- Often the success of a participatory project is due to the qualities of a particular person who facilitates or initiates the process.

Extract 18

“..in two studies where funding was provided by a consumer organization there was much more consultation and shared decision-making than in two other studies funded by traditional scientific agencies.”

Extract 19

“..networking with allies; starting slow and small, incentives to reward participatory behaviour in-house and in the field, easy access to information..”

Example from the literature: Peace (1999) ¹⁵⁴	Field: Social Care Group: Older people
The North Staffordshire Pensioners' Association approached a university department to ask if they would undertake a project for them about the 'real' living costs of older people on pensions. The academics did not agree to carry out the research, but offered to enable the group to conduct their own project. This attitude came about because the academic was influenced by feminist research philosophy. [The unintended consequences were that the group formed lasting friendships with some of their respondents and gained the confidence to fight other battles for older people.]	

Diversity

- Concern about representativeness should not be used to prevent involvement, but as an issue to be worked on.³¹
- Distinguishing between the types of representativeness considered by Barnes¹⁹ (and discussed in Section 2 of this report) will clarify issues about who to involve and why.
- ‘Stakeholder analysis’ enables different groups to be identified and their relative needs and hopes to be characterised. This process is undertaken in advance of a research project so that marginalised groups may be incorporated.^{46 67}
- It is important to recognise the differences between individuals within groups.²⁰¹
- Techniques should be used to get as wide as possible a range of views.¹⁹³ This process needs to be built in as part of the ‘relationship-building’ phase at the start of a project.

Values

- Commitment to a project must be on going, to protect the group from various agendas of the local professionals and agencies.¹²⁸
- Respect and trust emerges from the literature as a prerequisite for all successful partnerships; this is more likely to happen if the scale of the project is small (extract 20¹⁵⁸). Honesty is also seen to be necessary to overcome the threat of conflict and misunderstanding.¹⁸⁰
- Regular communication and information sharing is critical to relationship building and maintenance.²³
- Providing feedback of results to the lay people involved in a study is a good way to check that the information collected is trustworthy and has been accurately interpreted.^{60 120 210}
- Ethical values that enable empowerment as well as protection need to be incorporated in agencies’ guidelines.⁶
- Payment for work undertaken by lay people in research can be a motivating factor, or commitment to an issue may mean that lay people do not desire payment.

Extract 20

“Many small scale interactions about specific issues conducted in an open spirit would seem to be the way forward.”

Process:

Knowledge

- ◆ Lay people provide more accurate information, knowledge and understanding of their own communities than outsiders do (see extract 21¹⁰). It is important that researchers acknowledge and value different knowledge systems.
- ◆ Avoiding the use of jargon, acronyms and technical terms that are not accessible to lay people, simplifies the research process.¹⁸⁰
- ◆ Sharing knowledge involves disseminating results of projects widely in accessible formats. It also gives rise to other issues that make it important to consult lay people before this stage is reached (see extract 22⁹³).

Power

- Active involvement will change the agenda, so agendas must be flexible.¹²⁸
- Clarity of purpose about the responsibilities of all partners is required from the outset, as is clarity about the roles and relationships of partners.³¹
- Professionals need to “*make themselves vulnerable, rather than disguise mistakes*” and to make their “*own skills, knowledge and experience accessible rather than jealously guarded.*”¹²⁸
- There must be willingness by the powerful to give up their power.⁴²
- Power must be shared and lay people enabled to take action as part of the process.¹¹⁵ ***Lay involvement at as early a stage as possible is crucial for lay ownership of the project and satisfaction with the process.***^{169 190 170 191 153} ***Ownership by professionals is also crucial where they are charged to implement the results.***
- Advocacy is essential to bring about a shift in power relations.¹⁹²
- Following a lay agenda is more likely to be empowering for lay participants (extract 23⁵²p35).
- Power differentials between professionals and lay people should be overt and not hidden.¹²⁹

Extract 21

“To truly address problems, academicians, practitioners and community members are challenged to broaden their perspectives and see skills other than their own as complementary rather than competitive.”

Extract 22

“..having regard to the possible consequences of revealing information about less-powerful groups to powerful decision-makers [which may not] be in the interests of the community. Provide opportunities to check the interpretation of results with community members before dissemination; involve community members in devising recommendations, and demonstrate a commitment to see action taken on the basis of the results.”

Extract 23

“Another characteristic... which can be considered to contribute to a process of empowerment is that we follow the older people’s agenda.”

- People should be involved on their own territory, at times that suit them, using their language and in ways that reflect their own forms of social organisation.^{42 181}

Example from the literature: Barnes et al (1994) ¹⁹	Field: Social Care Group: Frail older people
<p>In order to enable frail older people to express their views, needs and experience of community care services and to influence future services, a panel of older people who used services in Scotland was convened in 1992. To facilitate meetings of these panels, comfortable settings had to be found, without incurring too long a journey for the participants. Accessible venues were vital, and transport appropriate. This included the provision of taxis and minibuses with hydraulic tail-lifts. The majority of people involved are in their 80's who live alone and are unable to get out without support. They are all regular service users.</p>	

Extract 24

“..the would-be researcher must be prepared to be proactive if their work is not to be buried and forgotten, and to build into their studies, timescales that allow considerable margins for delay.”

Extract 25

“The empowering step or bridge between reflection and action means creating a supportive community that can analyze successes and failures, identify obstacles, yet still maintain goals and motivation to address the root causes of powerlessness and disease.”

Resources:

- Recognition that lay involvement in research takes extra time and that there may be extra costs at the outset, has led some government departments to build in flexibility in their funding arrangements (see extract 24¹⁷²).^{31 66 96}
- Support should come in a variety of forms (see extracts 25²⁰⁴ and 26²³) including the provision of adequate resources to enable active lay involvement in research and ongoing support at the end of a project.¹²⁸
- A period of training for lay people is often necessary^{11 117 177 210} (for example in computer techniques for data processing), which they felt added to their skills and was an exciting challenge.
- **Joint training and learning is seen as essential**, involving lay people, professional practitioners and researchers.¹³⁶ The

inclusion of collaborative approaches in the course of professional training programmes raises awareness.¹²¹

Case Study 1	Field: Social Care Group: Mental health service users
A group of people with mental health difficulties took over the responsibility of evaluating Barrow Community Mental Health Gym ¹⁹⁶ further to training and support from university researchers who were initially involved in the research. Continuing support is available to them, as arranged by the researchers before their departure. This has given them the confidence to sustain their effort.	

Extract 26

“Support has four components: personal development, practical skills, practical support, support for people to get together. Support includes both personal and material support. Advocacy – speaking on behalf of others is a key form of support for people in dealing with agencies.”

- ***Expert facilitation is a necessary part of the process of involving lay people in research*** (see extract 27¹⁵⁴ p20).
Facilitators need specialised training in order to motivate lay people, and reduce conflict within and between groups that may already exist.
- Some funders value lay involvement in their selection of projects for funding, e.g. The Joseph Rowntree Foundation, DFID, The Sainsbury Centre for Mental Health, DETR (now DTLR).
- ***It is being recognised that working in partnership with others is not about the lowest price, but ultimately about best overall value for money.***

Extract 27

“We had two wonderful people...and their patience must have been terrific!”

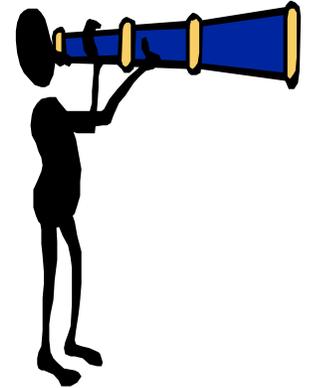
Example from the literature	Field: Regeneration Group: Multiple partners
<p>DETR guidelines for bidding for funding under the SRB state: <i>“It is crucial to ensure the active participation of local communities in the regeneration of their areas.. it helps to ensure that the benefits last over the long term by encouraging ownership of the scheme and identity with the area.”</i> Further, <i>“bids should engage the talents and resources of the whole community, including black and minority ethnic groups, young people and all sectors of the voluntary sector.”</i> In recognition that <i>“..it can take time to involve the community in the partnership and in development of the scheme, partnerships can opt to have a ‘year zero’... [to] ensure that local communities are properly engaged in the partnership.”</i> Up to 10% of the total approved grant can be spent on community capacity building projects, for example in training community representatives and providing community support workers to help community groups to develop skills. The document emphasises the importance of <i>“improving health through integrated regeneration strategies and on reducing inequalities in health and access to health and social care.”</i>⁶⁶</p>	

SECTION 2

6. The bigger picture

Included in this section:

- ◆ Ways of understanding and undertaking participatory research
- ◆ The aims and development of lay involvement
 - what is lay involvement in research for?
 - who currently gets involved and who should get involved?
 - ideas about lay involvement in research
 - the development of lay involvement in other fields
- ◆ Concepts that influence lay involvement
 - power and empowerment
 - language, meaning and knowledge
 - research values
- ◆ Putting lay involvement in a wider context
 - economic and political contexts
 - social and cultural contexts



This section of the report is for those readers who wish to know more about the theoretical issues that have influenced the development of lay involvement in research. The information has been taken from the many background papers that we discovered in our search through the literature and some from the projects described earlier in this report. Many of these come from the public sector in the UK, including health, social care, housing and local government. Where other fields are referred to, for example, overseas development, this is stated in the text.

Ways of understanding and undertaking participatory research

*“Research doesn’t have to be a mad scientist
– it can be a Madonna”¹⁷¹*

Much traditional research employs rigorous methods and strict controls to arrive at ‘the truth.’ ‘Telling the truth’ is a positively regarded value for which we all strive. Yet can we be sure that anything is true and do we all share the same truths? We can only say, at best, that current findings have so far ‘not been refuted’ rather than that they have been found to be true.¹⁵⁹ After all, for years people believed that the earth was flat. In recent decades, guidelines for healthy eating based on scientific ‘evidence’ have changed frequently. So much so, that it is sometimes hard to know what is best to eat. Some ‘truths’ simply reflect current political thought, and may change with the political climate.

Some suggest that the current state of our knowledge should be open to question in an on-going conversation of enquiry.²¹⁹ That is not to say that we can never find enough evidence to justify a particular decision. We are all likely to agree that under ‘normal conditions, water boils at 100 degrees centigrade’¹⁶² because it is a straightforward statement. Where complex social, cultural and political issues influence our understanding of the truth, then agreement on what constitutes the truth may differ from one individual to another.

The discussion leaves us with some questions about the way in which ‘evidence-based’ practice now equates to ‘good practice’ in the fields of health and social care. Frequently ‘evidence’ is narrowly interpreted only as ‘scientific.’ But there are other sorts of evidence, equally valid, that can be acquired by using different approaches to research and enquiry.⁸⁴

In order to explore the ways in which evidence is sought, we thought it might be helpful to look at the medical and social models of health. These two models present differing and sometimes opposing views of health and illness and tend to follow different approaches to research.

The medical model sees health as the absence of (clinically diagnosed) disease. The emphasis is on giving treatment for specific conditions, and counting numbers of successfully cured. The social model of health is commonly associated with the World Health Organisation definition: *“a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”*

222

The social model of health comes from an understanding that people are thinking, acting beings, and are part of a wider social and political environment. It is people’s experiences and understanding that gives an insight into the meanings they hold of health and illness. It is not so much about curing disease, but leading healthy lives and what health means to people in a local context (see extract 28⁸⁰).

The different models lead to different research traditions. The medical model traditionally involves conducting research using positivist (scientific) methods in strictly controlled conditions. The social model more often uses those methods regarded as qualitative, seeking meanings rather than statistics (see extract 29¹⁵⁸p109).

Definitions of research in the positivist tradition have tended to stress that research is about acquiring new knowledge that can be applied to many people and settings. The latest Research Governance Framework for Health and Social Care Research describes research as: *“..the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods.”*⁶⁴

Extract 28

A community view

“.. our practice area is very hilly and our response to the bronchitic and angina-ridden patients was to increase their medication. The project’s response was to negotiate with the local council to provide a bus route through the estate to Sainsbury’s!” (GP)

Extract 29

“Social scientists have long worked with the understanding that the knowledge they produce is value-laden, and have long since ceased to see their work in terms of opposition between science and opinion, between rationality and irrationality, passion and logic and commitment and detachment. Social scientists recognise that in studying the ‘life-world’ of individuals or the ‘culture’ of social agencies, a variety of rationalities and alternative discourses will be revealed.”

Extract 30

“There is too much measurement going on. Some things which are numerically precise are not true; and some things which are not numerical are true. Orthodox research produces results which are statistically significant but humanly insignificant.”

However, research involving lay people may be concerned more with ‘problem solving’ and ‘action’ than with acquiring new knowledge (see extract 30¹⁶⁴). It may also be more concerned with particular people in particular settings than with what is generalisable to wider populations. These extra considerations explain why we have used a rather broad definition of research in this scoping study.

Ways of Knowing

There are different ways of achieving knowledge about the world. These employ ‘qualitative’ and/or ‘quantitative’ methods of collecting information. Qualitative methods generally include unstructured or semi-structured interviews, participant observation, focus groups and other approaches. These involve researchers in actively listening to what research participants say. Quantitative methods include questionnaires, surveys, structured observations and experimental studies, including RCTs.

Extract 31

“The social relations of research production have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose.”

Participatory research methods are particularly difficult to classify. Working with lay people in communities may require various methods in combination⁹⁹ and such research does not necessarily follow a clearly defined course. Participatory research is not just about people taking part in the process. Most participatory research focuses on ‘knowledge for action.’ ***Its emphasis is on a ‘bottom-up’ approach with a focus on locally defined priorities and local perspectives***⁵³ (see extract 31¹⁵⁰).

Emancipatory research is also a participatory process, but goes further than participatory research. It sees *control* by lay people as an integral part of the process of empowerment.⁵⁰ The difference between participatory and emancipatory research is that improvement in the participants’ quality of life should result from emancipatory projects. Simply increasing participation and involvement by itself

does not constitute emancipatory research until people themselves decide who should be involved and how.^{128 226}

Many of the approaches used in overseas development today focus on the issues of emancipation and empowerment and may be referred to by a variety of names such as Participatory Rural Appraisal (PRA), Participatory Action Research (PAR) and Participatory Learning and Action (PLA). For a fuller description of these approaches, see the books; *Power, Process and Participation*¹⁷⁸ and *Participatory Research in Health*.⁵⁹

Perhaps our emphasis, then, should be not so much on the particular methods used (qualitative or quantitative) but on ways in which researchers and lay people can work together in a process that will be enriching, enlightening and will give a sense of ownership to all partners.

The aims and development of lay involvement

What is lay involvement in research for?

There are problems about the meaning of involvement or participation. It remains “*an elusive and highly problematic concept...*”⁴⁹ “*...since participation can mean anything from manipulation to user control, including non-participation and varying degrees of tokenism or degrees of power.*”⁷⁷ **As well as confusion over the meaning of involvement, there is often difficulty about its purpose especially in management-led initiatives to involve lay people** (see extract 32³¹).

Increasingly, lay people are concerned that researchers are taking insufficient account of public concerns about humanity, compassion, empowerment, social justice and sustainability.

Extract 32

“One central need is for clarity about the purpose of user involvement. There is often confusion about the role of particular ... groups and about what is expected of the individuals who volunteer ... to participate. This can lead to disillusionment and a reluctance to participate subsequently. Many of those participating in user committees were particularly unclear about their purpose and effectiveness. In consequence, expectations of action were dashed and feelings of powerlessness reinforced.”

We think that there are three particular ways in which lay involvement has the potential to improve and expand research in health.

1. Making a practical difference to people's lives and giving hope

All human beings engage in research or enquiry: we find out things in order to work out how best to adapt and cope with our every day lives. It does not have to be an obscure activity that only 'clever' people do. Yet academic researchers and intellectuals tend to value theory and knowledge creation over problem solving. For lay people, on the other hand, the purpose of research is more likely to be about trying to make a difference, to make things better, and to provide hope for the future.

One reason for involving lay people is that the standard approach to human services places an emphasis on the deficiencies of individuals, and undermines their sense of capacity and self-worth.⁷³ Focus on problem solving by outside experts can encourage passivity and decrease participation in and use of community resources, thus weakening community ties. As a result, people learn to be helpless, and may become isolated from the community and increasingly dependent on welfare services.⁷³

Lay involvement in research may mean that the problem solving aspect of research comes more to the fore, and that people together become more actively engaged in taking responsibility for improving their lives and conditions (see extract 33¹²¹). At the same time, it may mean that research attention is directed more towards social and economic change, rather than on expert and technical solutions.

Extract 33

“The therapeutic value of consumers' participation is based on the potential to increase self-esteem while strengthening coping mechanisms.”

2. Empowering individuals and communities

Concern over the failure of public services to meet people's needs and ensure equity of access has given rise to the development of research that gives priority to the views of service users.²⁰ This strategy emphasises the democratic ideal of community participation in public decision making. The democratic approach supports people speaking up for themselves about the issues that concern them.

3. Improving the quality of the research and its outcomes

Lay involvement may help to ensure that questions are asked in ways that make sense to participants and eliminate professional bias. It may also ensure that the right questions are asked and that the methods and tools used are acceptable. This should mean that more accurate information is gathered. Equally, lay people who want to involve professional researchers in their own research may do so to improve its quality by using expert advice and assistance. Lay involvement provides the opportunity for further debate about what society means by "good" research. It may also assist in wider dissemination and implementation of research findings.

Who currently gets involved, and who should get involved?

"People who live in disadvantaged circumstances have more illnesses, greater disabilities and shorter lives than those who are more affluent. Statistics everywhere reveal that death rates at most ages are two or three times greater in disadvantaged than in affluent social classes. The NHS must ensure equity of access to healthcare by distributing resources according to need."

In relation to service delivery, the most effective way to remove barriers to access is to empower individuals and communities to define their needs.”¹⁷⁵

There is evidence to suggest that only 20% of lay people ever become involved in matters of public interest.¹³⁰ At a strategic and policy level this is mostly men from professional and managerial backgrounds. At a grass roots level, this is more often women, except possibly in areas of high unemployment where men may come in and out depending on their employment situation. Consumer representatives within the NHS tend to be those who are sufficiently knowledgeable, confident, articulate, available and perhaps brave enough to volunteer. Rarely do those people who are most marginalised and who could most benefit from the research take part.

Extract 34

“A community is a web of relationships defined by a significant level of mutual care and commitment.”

Extract 35

“Community is: ‘A set of power relationships within which people are grouped.’ ”

People often become involved because they are dissatisfied with a service or they wish to defend one.¹⁵⁷ The Bristol Women’s Cancer Group, for example, was angered by the results of a flawed study that found their treatment centre to be ineffective.¹⁷⁹ Cornwall’s Healthwatch action group was established because of threatened closures of community hospitals.⁵⁷

Extract 36

Definitions of community:

- Communities of interest
- Geographical locations
- A value system about care involving reduction of dependence on institutions and professionals, greater control of services by users and smaller localised care units
- A mythical notion of self-sufficiency for all but acute and tertiary care

It is often the community, or those groups thought to represent the community, that is approached and whose involvement is sought. ‘Community’ itself has a variety of meanings (see extracts 34²⁰³ and 35¹⁴²). The confusion that can arise from different meanings of the term ‘community’ has political advantages, argues Heyman, who outlines four different definitions (see extract 36¹²⁴). Governments concerned to limit public expenditure may wish the public to view community care in terms of a “warm composite” of the first three definitions, while in their expenditure decisions, operating on the basis of the fourth.

Often in an attempt to hasten the participatory process, professionals will involve voluntary groups because it is easy to do so, but their views may not represent those of the whole community. Further, there may be little control over recruitment to voluntary organisations, and the motives of volunteers may not always be philanthropic. Some voluntary groups have been referred to as a ‘mafia’ of ‘professional users’ who exclude wider involvement.¹⁶⁸

We cannot assume that communities are in any way homogenous. The workshop that Folk.us members attended to discuss this project highlighted the fact that even within a ‘community’ of people sharing a similar disability, individuals may share concerns but prioritise them differently. Communities are complex and their needs diverse.⁴²

<p>Example from the literature: Vernon (1997)²⁰¹</p>	<p>Field: Social care Group: Disabled women/ethnic minorities</p>
<p>A research project was undertaken to understand the nature and extent of oppression experienced by disabled black women, given that, according to the author, this group is simultaneously subject to disability, race and gender oppressions. One of the respondents said that she <i>“had never been able to talk to anyone about her entire experience and feel understood as now because her non-disabled Black friends only understood issues around racism.”</i></p>	

Confusion about different meanings of the word ‘community’ has led to concerns about the extent to which ‘communities’ or members of communities can be regarded as representative of ‘the community’ as a whole. Marian Barnes et al¹⁹ usefully clarified the term “representative”. They distinguished between three different meanings:

1. The notion of a representative sample referring to the extent to which a sample deliberately selected by a researcher can be considered to represent a known population.
2. The notion of an individual or individuals, who can be elected to represent and be accountable to a particular group without necessarily sharing any of the characteristics of that group.
3. The sense in which the experience of particular individuals can be considered to be typical of those of many others in a similar situation and thus may “represent” a wider population by example.

Lay people who choose, or are invited, to become actively involved in research may not directly represent others, any more than professionals can be said or required to represent other professionals. Indeed, it could be argued that the influence of a variety of people with diverse views should lead to greater robustness in research planning and design.

It may therefore be necessary to include more members of communities in research rather than a few ‘representatives’. This would seem to suggest that small-scale local projects are the way forward for effective lay involvement. This highlights the need for a central body to collate the findings and disseminate them widely.

Ideas about lay involvement in research

Extract 37

“A shift can be traced from the consumerist approaches of the early 1990’s to a dominant concern with empowerment in the mid-1990’s and more recently to the growth of stakeholding.”

The welfare sector has undergone some diverse changes in the way that it regards patients or clients, ‘users’ or consumers and more recently, stakeholders (see extract 37¹⁷). Behind all these terms lies a philosophy about the way lay people should be involved in their health and social care.

The welfare principle that governed the public sector until about a decade ago was based on the paternalistic premise that 'professionals know best'. The consumerist approach of the early 1990's was a direct product of the White Paper, *Caring for People*,⁶⁵ which had the aim of moving people from being recipients of welfare to being active consumers (the marketing model). The principles guiding health and social care became those of the market place. This came with the ideal that people would have real choices about the types of services they bought (see extract 38⁸⁹).

Extract 38
"Consumers are the ultimate recipients and beneficiaries of the knowledge derived from research and development. It is therefore not only desirable, but essential that they be involved in developing and implementing strategies for R&D in the NHS."

Consumers were expected to be able to make decisions based on information provided by professionals. But this philosophy was found to be flawed because the market was at best a 'quasi market',¹²⁶ in which users had little or no choice and did not control the funds which would give them power.

Consumerism failed many groups of people, for example those with mental health problems, learning difficulties, older people and the homeless, as they remained remote from the decision-making process. A more radical democratic model has therefore evolved, which embraces the concept of empowerment in a way that consumerism could not (see extract 39⁹⁷p9).

Extract 39
"The consumerist approach is associated with a reform agenda and linked to the New Right, whereas the democratic approach has been seen as more radical and linked with the emergence of disabled people's groups, self-advocacy and civil rights organisations and movements."

Groups of people do, however, continue to be disempowered. There is often professional resistance to empowerment. From the mid-1990's the emphasis moved from empowerment to partnership, which was seen as less threatening and antagonistic to professionals.¹⁴⁴

Stakeholding is a term that was devised to emphasise people's rights and responsibilities as partners, and offers all those with a 'stake' in the service the opportunity to participate. It acknowledges differentials in power without demanding equality. It requires an agreement about roles and responsibilities and an understanding of where power is located. Empowerment may be achievable by lay people, but is not

the primary aim of stakeholding. *“What is important is that the users’ voice is heard, their perspective is valued and their views have influence.”*¹⁷

Different stakeholders will clearly have their own perspectives on the aims and objectives of research. For purchasers, success may be finding the most cost-effective treatment or intervention, whereas cost-effectiveness may not be a priority for lay people.¹⁵⁶

The confusion and inconsistency around these philosophical ideas about lay people as patients or clients, consumers or partners in their relationship with public services, may hinder the progress of active lay involvement. What is important is that the aims of involvement should be clear to all stakeholders, and the commitment to participation itself must be wholehearted (see extract 40¹⁰⁰p45).

Some academics are now writing about ending inequality and taking the side of oppressed and marginal groups in research. Their ideas, though important, are often expressed in ways that can seem off-putting because they are complex and challenging. A range of influences including feminisms, black perspectives, critical theory, humanistic psychology, and Paulo Freire’s notions of education and social action are well outlined in the book *Research and Inequality* by Truman, Mertens and Humphries.¹⁹⁵ Overall, these authors try to identify what research can do to facilitate social change towards increased social justice. These ideas are of key importance for health research, given that an important aim of the NHS is to reduce health inequalities.

Extract 40

“Healthcare is often no longer the intimate relationship of the doctor and the patient of the paternalistic model...As the traditional authority of the medical profession is undermined and patients become more confident, a different basis for the contact...is needed. Ultimately the relationship of health professional and patients needs to be based on mutual trust between equals, and involves professionals and patients redefining what they mean by ‘best interest’.”

The development of lay involvement in other fields

In fields other than health, the development of the principles of lay involvement in service planning and provision, and, subsequently, research came a little earlier, but tracing the path of this development is not easy.¹⁰⁹ According to Jewkes and Murcott, community participation became a common feature of overseas agricultural development programmes and work with the urban poor during the early decades after the Second World War. This was taken up by the World Health Organisation and the World Bank and applied to health and medicine in the developing world, identifying the importance of encouraging community participation in the planning and implementation of health programmes.¹⁰⁹

In the UK public sector, the development of lay participation had its beginnings before the 1980's, but in that decade it started progressing more rapidly with the political shift in emphasis from paternalism to 'active' citizenship, and in the 1990's to 'community care.' The 1980's saw the rapid rise of the 'user movement' particularly among groups of mental health service users, people with learning difficulties and people with physical disabilities. These groups often developed a more radical voice in the face of what they perceived as having little control over the services they received. For a discussion on user movements, see M. Barnes, *Care, Communities and Citizens*.¹⁸

In the UK, community development projects emerged in the 1960's as the government's response to the realisation that poverty had not been eradicated by the setting up of the welfare state, and that a concerted effort would be necessary to combat deprivation.¹⁸⁵ Lay involvement initiatives in this field grew during the 1990's, with the emphasis being on joint-agency working with local groups of people to improve the environment, encourage regeneration, and foster 'community spirit.'

Concepts that influence lay involvement

Power and empowerment

“So the user movement experiences now a paradoxical situation. On the one hand, the DOH embraces user empowerment, through circulars and other publications, exhorting health and local authorities to involve service users in planning and management. On the other hand, users are being disempowered as a result of negative press coverage, legislation offering further powers of compulsion and of service models prescribed from the DOH. Just as partnership with users becomes one of the cultural norms of local health and social care agencies, the range of issues over which users can exert influence may be diminishing.”¹⁵⁵

Extract 41

“The gatekeeping agency as a whole has considerable power over the researcher in terms of facilitating access to clients or records and thereby may ultimately influence whether the project succeeds or fails.”

Extract 42

“Almost by definition, the poor and powerless have no voice. It may be politically correct to say that they should be empowered and their voices heard. But cynical realists will point to inexorable trends, vested interests and pervasive self-interest among the powerful, and argue that little can be changed.”

There is divided opinion about who wields the power in research. Is it the professional or lay researcher who controls the process, the practitioner who controls access to lay people in their care, or the commissioner/funder of research? For some, *“power will depend on who has the information and money. It will also depend on people’s confidence and skills.”*¹¹³ Others feel that where professionals lead the research, they *“are more likely to involve and empower service-users if they do not feel disempowered themselves,”*²⁰⁰ but that, even so, the professional agency still has more power than the researcher (see extract 41¹³⁵). Whatever the answer, power is unlikely to rest with the lay person unless their involvement is truly active (see extract 42⁴⁴).

A feeling of disempowerment might motivate people to become involved in research, yet so often people are not aware of being oppressed and even if they are *“..we operate in a social structure*

which seeks to silence all oppressed groups, and neutralise any criticism or protest."²²⁶

The concept of empowerment is a difficult and elusive one. It means different things to different people in different contexts. The notion of empowerment includes ideas such as 'being in control', shifting power, participation, choice and involvement. An ultimate goal of lay involvement in research may be to gradually adjust the differential power relationships between professionals and lay people in order to equalise the balance of power.¹⁶⁵

According to Barnes and Warren,²⁰ empowerment was one of the buzzwords of the 1990's. They go on to say *"no respectable academic, policy or practitioner discourse is complete without its nod in the direction of the empowered consumer, the empowered citizen or even the empowered worker."* But they warn that the language of empowerment often seems to substitute for changes in practice.

So what is the potential for lay empowerment through research? The following example illustrates how the process of research can be empowering, but also indicates that this empowerment may fluctuate during the process and may not be sustained when the research is finished.

Example from the literature: Travers (1997) ¹⁹²	Field: Health Education Group: Parents
<p>This research project took place in a family centre in Canada, and aimed to initiate education about nutrition for poor families, and reduce inequalities of access to affordable healthy food. Led by a researcher, a group of women were empowered to organise local actions on supermarket pricing inequities. The process of health promotion moved on but did not quite achieve action at the level of public policy. Although the feeling of empowerment was not sustained, the women's involvement was a learning experience that no one can ever take away from them.</p>	

How can we link participation in research to the process of empowerment? One way might be through the use of a visual model, looking at the types of approach to participation and evaluating how empowering these may be. A number of models have been put forward to describe the process of empowerment, whether by participation in research or in service planning and provision.

Extract 43

“the typology does not include an analysis of the most significant roadblocks to achieving genuine.. participation. On the powerholders’ side, (the roadblocks) include racism, paternalism and resistance to power redistribution. On the have-nots side, they include inadequacies of the poor community’s political socioeconomic infrastructure and knowledge-base, plus difficulties of organising a representative and accountable citizens’ group in the face of futility, alienation and distrust.”

An early model was proposed by Arnstein⁷ in 1969, as an eight-step ladder of involvement ranging from non-participation on the bottom rung, to delegated power and citizen control at the top (see Annexe G). ***The model shows that there are gradations of participation, not of all which will be empowering.*** Consultation, for example, often thought to be a desired aim of participation by public bodies, is no more than tokenism according to this model. So empowerment can be seen as both a process and a goal by which the roles of lay people are adjusted along a continuum of involvement. Arnstein warns, however, that the ladder model has limitations (see extract 43⁷).

Cornwall⁵⁴ adapts several models to form another more inclusive one that applies specifically to the research process. The model has six levels representing types of participation in the research process and

the relationship between researcher and researched. These take us through 'top-down' approaches of co-option and compliance (research 'on' or 'for' lay people), to partnership working in consultation and co-operation (research 'for' or 'with' lay people), to empowering alternatives of co-learning and collective action (research 'with' or 'by lay people) (see Annexe G).

The disadvantage of these models is that they simplify a complex process and portray it vertically which, unfortunately, can reinforce notions of hierarchy. The advantages are that they offer a framework for researchers to work with.

Empowerment of lay people often needs to be facilitated by professionals, and this has implications for challenging the way organisations work (see extract 44¹²⁸). In gaining power, there is a notion that lay people will benefit in a number of ways (see extract 45¹³²), and that they will own the services they receive and take responsibility for their own care (see Beresford & Croft²³ for a good discussion about how empowerment may be achieved, and how not to do it).

One of the difficulties with empowerment is that it may involve someone else giving up power. Chambers suggests that personal disempowerment can be a gain in several ways. Firstly, it brings liberation and peace of mind, and then as it offers new roles it can also bring effectiveness to the research process. Secondly, he suggests that power on a pinnacle can be lonely. Equal relationships are more satisfactory. Participatory styles of management can be fulfilling; the losses being more than compensated by gains. Finally, disempowerment can be fun.⁴³

Extract 44

“Routine organisation practices, top-down planning, and standardisation of services reflect dominant values and patterns of power, and a lack of choice, such that in terms of type and level of provision, services fail to meet people’s needs.”

Extract 45

“When people form a group with a common purpose, investigate their situation and make decisions.. [they] are transformed – losing fear, gaining confidence, self-esteem and direction.”

Language, meaning and knowledge

“Language raises many issues for involvement. Central is its relation with power. Language is not neutral. Labels like ‘the old’, ‘the unemployed’, ‘the mentally ill’ are imposed upon people.”²³

Extract 46

“The assumption is that ‘better’ (objective, rational, highly credible) knowledge will have greater influence.”

Extract 47

“It is important not to use jargon, abbreviations, acronyms, tradespeak, customs and rituals and complex timetables and agendas which can lead to the exclusion of non-professionals in the business of meetings.”

The way in which we use language reflects, in part, the way we see the world. Different ‘communities’ may share a common language, and common knowledge. Professional groups have their own vocabularies, which relate to their ‘specialisms.’ Along with this terminology goes a body of knowledge that professionals have (or believe themselves to have) and that lay people do not. Professionals retain the belief that this knowledge is somehow superior to lay knowledge (see extract 46⁸²). ***This can create problems for partnership research, where it is important that all partners speak the same language and understand each other’s meanings.*** Although it is recognised that specialist terminology should not be used in meetings with lay people (see extract 47¹⁶⁵), it is hard to avoid¹⁸¹ and may sometimes exclude people.⁶⁹ ***The potential contribution of lay knowledge to the research process is often devalued or ignored.***¹⁹⁵

Example from the literature: Rhoades & Booth (1996) ¹⁶⁶	Field: Overseas development Group: Farmers
<p>In Peru, seed storage technologists were working to determine how to increase the amount of seed potatoes successfully stored by local farmers. The first problem was that the farmers did not agree with the ‘experts’ about what constituted a spoiled potato. Farmers had a variety of uses for potatoes that the ‘experts’ regarded as ruined. Finally, experts worked with farmers to build storage trays that the farmers could afford. Once they were able to agree on a problem and a solution that was simple for the farmers, then farmers were willing to be co-operative. This is an example of the ‘farmer-back-to-farmer’ approach in development research. This has been translated into the ‘participant-back-to-participant’ model by a researcher in the US working with people who have learning difficulties.¹⁷³</p>	

At the present time, with government policy dictating joint working by agencies, professionals may feel threatened that their knowledge base is being eroded by the need to share with other professionals and lay people. It is also argued that the preservation of special language and mythology can be advantageous to organisations and professionals if it serves a specific social purpose to the group.¹³⁶ This ‘tribalism’ separates groups of professionals as much as it divides professionals and lay people.

Thus we can see a picture of competition between different groups of professionals, characterised by differing understanding of language and different knowledge bases. **People also come from different backgrounds and have different experiences. This will influence the value they place on activities, the findings of research and the way people look at research. This becomes particularly important across age, gender and ethnic divides.**¹⁹⁵ Considering that minority ethnic groups comprise 6% of the UK population,¹² an

even greater potential communication problem exists where English is not the lay person's first language.

Lay people who seek to become involved in the research process are, therefore, not only challenged to learn a new language (or two) and new meanings, but also to break down traditional power hierarchies. What is often overlooked is the need for professionals to understand lay knowledge and language without devaluing it.²⁴ ***One way of breaking down language barriers is to use research techniques that rely more on visual images than language to represent common ideas or themes.***

Extract 48

“Professional realities present much of the problem, valuing things over people, measurement over judgement, reductionism over holism, with a dominant cult and culture of economics, all combining to create a professional prison.”

Extract 49

“People's values and aspirations are complex, diverse and dynamic; and they cannot be known by outsiders without enquiry, without enabling local people freely to undertake and share their own analysis. When a poor rural woman in Zambia was asked what her dream was, she said it was to have time to go to town and spend time with her friends.”

Research values

In conventional research the researcher is expected to be a 'value-free' objective person in the process of discovering truths about others. It is widely believed now, however, that there is no such thing as value-freedom. We all have some personal values, and try as we might, it is difficult not to take them into the research arena.

Decisions about which researchers should study which people, and which research methods can be used all depend on value judgements being made by someone somewhere. Professional values are often different from lay values and are criticised by Chambers as being irrelevant to people's needs, whilst at the same time creating a prison for professionals (see extract 48⁴²). We have already cited an example from overseas development where professionals and lay people could not agree about the definition of a 'spoiled potato.' Many other examples come from this field, some of which are ably illustrated in Robert Chambers' book, 'Whose Reality Counts' (see extract 49⁴²p179).

In participatory research shared values and honesty are key goals. These lead to trust, which is a vital component of any successful relationship. Yet in research this is often overlooked. Researchers talk to participants about deeply personal areas of their life, without having the opportunity to build a trusting relationship first (see extract 50⁷⁹).

Often this is due to funding constraints. Indeed lack of funds and lack of time, two issues that are often interrelated, probably account for the failure of many participatory research efforts. A number of writers on lay involvement refer to the building of trust, understanding and providing supportive networks as essential to the process of empowerment^{23 53 204} as well as being honest about the limitations of research (see extract 51⁵³).

Building a good relationship requires a significant time commitment at the beginning of the project. It has been suggested that researchers and community members must make this time commitment even when they are not fully compensated.¹⁰ Yet the issue of payment for time given voluntarily by participants and researchers alike is an important one. If equal value is placed on all partners, then arguably all should be paid for their commitment.

Extract 50

“Feeling safe and being able to trust the person to whom they were talking was very important because the issues being discussed were personal and related to a time in their lives when they had either been in trouble or were having problems. Recounting this to a stranger with other strangers present was not something with which they seemed comfortable.”

Extract 51

“Practitioners need to tread a careful path between generating sufficient interest for participation and not raising false hopes. Identifying honestly the limitations of what can be achieved at the outset is an important part of establishing trust.”

Case Study 3	Field: Community Development Group: Local people
The local people recruited for the Briardale Community Centre project ¹⁷⁷ stated that the major factor that attracted them to becoming involved was payment for their work, at a level that would not affect benefits payments. However, once they learned more about the project this was less important.	

Case Study 6	Field: Community Development Group: Local people
Members of the Totnes Traffic Appraisal Group did not want to be paid for the time they spent gathering information as they felt that their commitment to solving the traffic problem was sufficient.	

Extract 52

“Early medical ethics guidelines were about etiquette: relations with colleagues, and promoting public respect for the profession. Some of these standards benefited patients, but a main concern was also to benefit the medical profession.”

Issues about values also lead us to question the ethics, or moral values, of research. *“Traditionally, research ethics have been concerned with potential harm to participants as the results of certain practices; for instance, the use of deception or lack of confidentiality. Less often identified are the human rights issues involved in treating people as objects – receptacles for the ‘data’ which are ‘extracted’ by research instruments – or in representing participants in ways that distort their experience (e.g. through discounting their language), or in excluding participants from any input into the research process.”*²²⁰

Extract 53

“The Canadian Research Ethics Committee code of ethics is based on the view that humans are rational beings. An ethic of care, on the other hand, is based on that view that humans are relational beings. Being relational means that at the forefront of decisions about what is right, are caring relationships with others. Principles based on an ethic of care are fundamental to the Participatory Action Research (PAR) (approach), and this needs to be taken into account in ethics committee guidelines”.

Ethics committees have been set up to govern the conduct of research in some fields but not others. Nowhere, however, are they as highly developed as they are in the field of health (extract 52⁶) which is why we begin our discussion on ethics by talking about Local Research Ethics Committees (LRECs) in the NHS. Many other ethics committees take their lead from medical research ethics guidelines, stimulated by the Declaration of Helsinki.²²³ LRECs in the NHS scrutinise research proposals and focus on issues like degree of risk or harm, consent procedures and issues of confidentiality.

The ‘protection principle’ which guides these ethics committees may conflict with the principles of empowerment that lay involvement in research seeks to promote (see extract 53¹⁸⁴).

People who are consumers of services are often vulnerable due to illness, disability or poverty and arguably *do* need protection especially where their understanding of the research process is incomplete; the protective function of ethics committees is clearly

essential. Yet ethics committees could also play a role in promoting the values of empowerment.

The process of obtaining ethical approval for a health project is a lengthy one, which requires an understanding of the terminology used in the application form, as well as the provision of substantial amounts of information that lay people may not be able to access. ***For participants, too, ethical approval forms can seem more designed to protect the researcher from litigation than for the participants.*** In one study in the field of mental health, the researcher who was trying to move towards a more collaborative research process, noted that *“many of the participants found the consent form confusing in terms of language, layout and ideas”*.⁴¹

Adapting to change is a slow process. The altered focus of research, increasing involvement of lay people and new methods now being used must all be accommodated. In other countries (notably the US, Australia and Canada) these changes are being encompassed in health research ethics.⁸¹ Australian and Canadian Ethics Guidelines are increasingly recognising the importance of community participation.^{86 141}

There is an indication that research in other fields is not guided by the activities of formal ethics committees, but rather negotiated locally by partners (see extract 54²¹⁴). In social care, the SSRG has produced a ‘Code of good practice for research, evaluation, monitoring and review studies in social, housing and health studies.’² This document appears to offer flexibility and is responsive to local initiatives, trusting local researchers to be guided by the code of practice and their own human values. It also has the advantage that research can be undertaken without going through a complex and time-consuming process. Through this process the involvement of lay people in research is quicker and easier to secure. But it does raise some questions. Are participants open to exploitation or abuse? To take

Extract 54

“Participatory research is strengthened by local, jointly negotiated, ethical codes or agreements that ensure the sharing of leadership, power and decision making from design to dissemination.”

just one example, police checks have to be carried out on social care professionals who work with children, but not on researchers at the present time.⁶

The activities of ethics committees are not the only considerations. There are a number of other general ethical issues to be considered in research that actively involves lay people. One of these is the importance of openness with prospective participants. Agendas should be on the table, and not hidden. Another is that if whole communities are expected to benefit from research, they should have the opportunity of becoming full partners. A further aspect of ethics that needs to be considered by those undertaking participatory research is that of not building up people's hopes by making false promises. Recently, the issue of ending the research has been taken up¹⁴⁷ and issues around doing research with lonely people.²⁷

Example from the literature	Field: Social care Group: People with learning difficulties
Wendy Booth ²⁷ describes two projects in which she became involved with people with learning difficulties and their parents. One of these projects was about developing advocacy support for parents with learning difficulties. The project continued for 18 months, and she was in contact with the parents three or four times a week. Careful strategies for withdrawal were worked out well in advance of the project's end, to make sure that support systems were in place afterwards. But she states that four people had decided to stay in touch with her and have continued to maintain contact for seven years. She says: <i>"For me, participatory research with people who have learning difficulties is not simply about enabling their inclusion but also about living up to the longer-term commitment that such a stance might bring"</i> .	

Bob Holman¹⁰² suggests a number of wider ethical questions that should be asked when involving lay people:

- Who owns the research?
- Who defines the issues to be researched?
- Who decides how the topic should be researched?
- Who interprets the findings?
- What role do respondents play in data collection?
- For what purpose will the research be used?

(Adapted by Taylor¹⁸⁵)

For a good discussion of ways in which the working of medical ethics committees could be improved, see chapter 4 in Hogg's book, 'Patients, Power & Politics.'¹⁰⁰

Putting Lay Involvement in a wider context

“Agencies can help empower people. But this must be put in context. That context is often disempowering. Racism, sexism and other oppressions are endemic in our society. Organisations aren't islands. They reflect these broader problems as well as posing their own. It isn't just a question of awkward agencies, individual customers being ignored or organisational problems. Whole groups of people are disadvantaged and disempowered. There are widespread economic, political and social inequalities at work. The more that political power is centralised and economic power unequally distributed, the less say people are likely to have.”²³

The involvement of lay people in research occurs within wider political, economic and socio-cultural contexts. But we are all products of wider systems and it is hard to see things as they really are. As these factors are complex, we have tried to separate them into the

'economic and political' and the 'social and cultural', but there is considerable overlap.

Economic and political contexts

"It is unwise to pay too much, but it is worse to pay too little. When you pay too much, you lose a little money – that is all. When you pay too little you sometimes lose everything because the thing you bought was incapable of doing the thing it was bought to do. The law of business prohibits paying too little and getting a lot – it can't be done. If you just deal with the lowest bidder it is well to add something for the risk you run and if you do that you will have enough to pay for something better." John Ruskin 1819-1900

We all want smooth running, efficient, effective public services that afford equal opportunities of access. But resources are finite. The source of funding dominates the overall direction of research. In health research, funding comes from the government, charitable foundations and commercial interests. According to the Association of Medical Research Charities in 1992-3, 56.3% of health R&D was funded by the pharmaceutical industry, 12.9% by medical charities, 10.2% by the NHS, 9.3% by universities, 8.1% by the MRC and 2.7% by the DOH.¹⁰⁰

Looking at the charitable sector alone, some of the research commissioned and/or undertaken by medical charities has a quality of life focus (for example the Alheimers Society³). Other charities still primarily concentrate on drugs and treatments (for example the Cancer Research Campaign¹). The scope for lay involvement varies considerably, with some charitable organisations following a medical model and some including social aspects of health and well being. Since by far the majority of funding comes from drugs companies, the

major thrust of health research must be more about medication than about people.

Certain areas are targeted for government funding because their communities are particularly impoverished. Areas have been designated as Health Action Zones, Education Action Zones, and areas targeted for regeneration under the Single Regeneration Budget and the New Deal for Communities, plus funding under the Healthy Towns and Cities initiative instigated by the World Health Organisation.²²² Additionally, lottery funding is granted to a variety of community groups for a number of purposes including the establishment of Healthy Living Centres, but groups find it difficult to negotiate the complex rules and requirement for matched funding that some sources require.³⁵ Many of these initiatives have implications for the health of communities, and offer opportunities for cross-boundary working.

Funding from these various sources have led to a proliferation of projects in many fields. Some small voluntary organisations, often consumer groups, are granted research funding and team up with academic or independent researchers to help them through the process. This adds a further dimension that contributes to the fragmented nature of many short-term research efforts (see extract 55¹²⁷). ***This also has implications for professional researchers, who build up a body of knowledge and expertise during the lifetime of a project but then move on to other work.*** The possible consequence for lay people is that there is often no time to plan and implement effective involvement, and no continuity.

Universities too are in competition with each other for research funding to add to their prestige and increase their standing in University league tables. With this element of competition, money is likely to go to the lowest bidder, which sometimes means that corners are cut, and budgets are insufficient,

Extract 55

“A large proportion of research being carried out within the higher education sector is funded by external bodies of some kind, on short-term contracts. The argument is put that little time and energy goes into the management of this contract research. The combination of high staff turnover, little management and the decline of the dual support system, have made it increasingly difficult for relationships between researchers and users to build up.”

particularly as lay involvement often requires more time than some conventional research.

The example below illustrates that the importance of working in partnership with others is not about the lowest price, but the best overall value for money. Although it comes from the construction industry, the principles can easily be applied to health service R & D.

Example from the literature	Field: Social Housing Group: Construction industry, consultants and social landlords
Recognising the limitations of the tendering process in bids to build social housing projects, a DETR taskforce was set up in 1998 to look at partnering arrangements within the industry. The aim was to “ <i>challenge the waste and poor quality arising from our existing structures and working practices.</i> ” They introduce the concept of partnering, which involves the development of long term partnerships between builders, designers and social landlords based on expertise, mutual trust and accountability. Selection of partners should be “ <i>on the basis of attitude to teamworking, ability to innovate and to offer efficient solutions.</i> ” ⁵¹	

There is evidence that some government departments are taking on board the special requirements needed to involve lay people in partnership exercises. DFID now insists that sustainable benefits to the community are built in to bids for research funding at the proposal stage. Their funding can accommodate open-ended ‘process’ research as well as the more traditional time-limited ‘blue-print’ research.⁹⁶

Social and Cultural contexts

Social and cultural contexts are inter-linked with the economic and political, but there are particular influences here that operate within and against wider systems. There are many different cultures. We often hear the term 'western culture' used to describe all developed societies as though they were a homogenous group. But there are cultures within cultures even within a small rural community, never mind a whole country.

We still live in a hierarchical society. The consensus view is that we are socialised to 'know our place' and accept our position in the social class system, and our status in the groups we belong to. At the other extreme, the conflict view is that the underprivileged must overthrow the current hierarchical system and raise awareness of the plight of oppressed groups (extract 56⁵³). Whichever view we subscribe to (and there are many others) will determine the nature of our social relationships and the kind of organisations to which we belong.

Extract 56

"Tools for gender analysis within Participatory Rural Appraisal (PRA) have been developed over the last few years. Yet while the voices of women might be listened to during the PRA process, pervasive males bias within institutions using PRA remains largely unchallenged."

In the research arena, there are a number of different players. There are lay people, professional practitioners, and researchers, both academic and independent. They all bring their different cultural perspectives to the arena. The differing social and cultural contexts, within which lay people and professionals live and work, may mean they have different priorities for research and may want different outcomes. For example, most cancer trials are about chemotherapy. However, one survey found that women with breast cancer wanted more research on the impact of treatments on their quality of life, environmental issues, psychosocial issues and the optimum dose of radiotherapy required to control the tumour while at the same time causing minimum damage to healthy tissues.⁸⁵

These different perspectives may fuel professional fears that lay people are unable to agree on priorities for research and will not have

the same opinion as them about which are the more urgent problems. However, Blaxter's review of consumer priorities revealed that public values about services are quite consistent.²⁶

Community and voluntary organisations will have varied perspectives on lay involvement. If health professionals tend to follow a medical model of health, then some, but by no means all, charitable institutions may follow a charity model. This is about helping people who are less able or less fortunate, but is no less paternalistic. User groups, on the other hand, tend to follow a social model of health, and are sometimes radical in their quest for change. User groups may differ from traditional voluntary organisations operating within the welfare sphere. Some have their origins in opposition to voluntary organisations that claim to act 'for' disabled people and others, without being directly controlled by the people they claim to represent. These groups are highly diverse, and as with voluntary organisations, they may be dependent on the enthusiasm of particular individuals. Like other voluntary organisations, they differ widely in size and structure.²⁰

Extract 57

“A repeated experience with (participatory research) has been the tension and contradiction between top-down bureaucratic cultures and requirements, tending as they do to standardise, simplify and control, and demands generated at the local level tending as they do to be diverse and complex and to require local-level discretion.”

Chambers⁴² has identified different and conflicting statuses given to professionals in health and research. The emphasis for medical professionals is cure, and for academics is understanding. According to Rawson¹⁶³, the “*nature of professions incurs hierarchy and separatism.*” Professional cultures may therefore be in conflict with each other, and lay culture will add a further, perhaps more practical, dimension (see extract 57⁴³).

For participation to become part of an institution's culture, the challenge is to place “*bottom up, collaborative and decentralised approaches into organisations that are historically top down, centralised and hierarchical*” and this is seen as problematic according to Kar, Lunstrom and Adkins.¹¹⁹ Although these authors were working in the field of overseas development, parallels can be

seen in the challenges posed to the equally top down, centralised and hierarchical public sector organisations in the UK. The authors then go on to talk about the conditions that are necessary to achieve participation. They believe that three requirements are necessary:

- ***The first is a political environment characterised by democracy and decentralisation.***
- ***The second is support by local leadership for changing their institutions, by relearning and realising the capability of lay people and the richness of local resources.***
- ***The third is the facilitation capacity for community based planning and management, with sufficient participatory research practitioners to undertake this work.***

Recognising these factors has led some to challenge organisations to change their cultures (Extract 58¹¹⁵), not just the structures, *‘the people and bricks and mortar too’*²³ (and see extract 59¹¹⁶). The more rigid and hierarchical an organisation, the less likely it is that democratic principles will be applied to research.

Research into lay perspectives has been facilitated by organisations committed to giving a voice to lay people and who are responsive and flexible in their approach to research. Sometimes this can be a local office of a national agency, or can arise from the democratic qualities of particular individuals.

Extract 58

“The central aim of community involvement will not be achieved unless existing mainstream bodies – from government departments to local management boards – accept a change of culture within their organisations.”

Extract 59

“Public sector cultures need to be changed from top to bottom if communities are to be given real power and responsibility to take action.”

Example from the literature

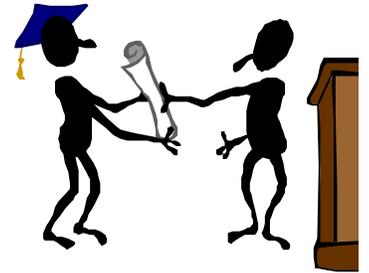
Field: Social Care

Group: Older people

An organisation called 'Help and Care' that works with older people in the Bournemouth area received funding from the local Social Services Department to look into barriers to independence for older people. The arrangement was flexible, and older people from a variety of different groups in the area were asked how they would like to undertake the research. The group of older people decided on the method used, interviews, and also decided they would like to conduct these interviews themselves, analyse the data and possibly write the report. Implications for relationship building within the group and training for group members meant that Help and Care had to re-negotiate with the funding agency, to allow extra time for the project. To date, all additional requirements have been met. The project is still in its early stages.

7. Lessons learned and recommendations

This chapter describes the main lessons learned from our review of the literature and visits to case studies. These seemed to the research team, the project steering group and members of Folk.us to be fundamentally important in achieving active lay involvement in research. The lessons are not presented in any order of priority. We have categorised them under the following headings:



- **Contexts**
- **People**
- **Process**
- **Resources**

Alongside the lessons learned we have made some recommendations.

These are for the following groups to take into account when considering active lay involvement in future research and practice:

- professional and lay researchers 
- funders and sponsors (including the Department of Health and NHS R & D) 
- service providers 
- Consumers in NHS Research 

The symbol for each group appears alongside recommendations aimed at that group.

Lessons learned

Contexts

1. Conditions that facilitate participatory research include political democracy, local leadership support for changing institutions and the capacity to facilitate community-based planning and management.
2. Participation in research will not always be empowering, especially when broader empowering conditions are not in place.

Recommendations

- ☺ Procedures and mechanisms should be put in place by funders and sponsors of health research to ensure that the commitment to lay involvement in research is turned into a reality. Such procedures already exist within other government departments, e.g. DFID and DTLR.  

People

3. Equal value should be given to lay and professional knowledge.
4. Lay people are able to understand and respond to complex research issues more than is often thought.
5. Both lay people and professionals need to negotiate common problems and solutions, to ensure the co-operation of all parties.

- ☺ Researchers should respect, value and take into account lay knowledge on the relevant topic. 
- ☺ Professionals/researchers should ensure that complex or technical research issues are presented to lay people in formats and terms that are accessible to the particular group of lay people involved.  
- ☺ In order to identify common problems, researchers should work with smaller groups at a local level.   

- | | |
|--|--|
| <p>6. Lay people are able to understand all aspects of the research process providing it is presented to them in accessible formats.</p> | <p>☺ Creative ways of presenting information and disseminating findings should be sought. For example, picture formats for people with learning difficulties.  </p> |
| <p>7. It is important that all partners in research understand each other in terms of the language they speak, as well as jargon used by particular groups.</p> | <p>☺ A glossary of commonly used terms and definitions in research should be produced (by professionals in collaboration with lay people) so that everyone is clear about meanings. This is already being done at a local level in the South West, but needs to be agreed nationally. </p> |
| <p>8. There is a need for clarity within a research project about</p> <ul style="list-style-type: none"> • the motivation behind working in partnership • the roles and responsibilities of partners • the aims of the project, in order that expectations are commonly understood. | <p>☺ Funders and sponsors should develop a clear definition of what is meant by lay involvement in research, and include it within guidelines such as Research Governance. This should encompass the power-sharing philosophy of participatory research. </p> |
| <p>9. Representativeness is a complex notion with a number of meanings.</p> | <p>☺ Researchers need to clarify what sort of representatives should be included for different purposes. </p> |
| <p>10. It is necessary to include a range of members of a community rather than just a few representatives.</p> | <p>☺ In order to include a range of members of the community several small-scale projects should be undertaken.   </p> |

<p>11. Participating communities are not born; rather they have to be cultivated and require effort to engage.</p>	<p>☺ Researchers should consider undertaking a stakeholder analysis or other systematic method of identifying key groups whose involvement is necessary in each project, following guidelines laid down by DFID. This will also ensure that the needs and aspirations of these groups are taken into account. </p>
<p>12. When lay involvement works well it enhances relationships between partners and increases mutual respect and trust.</p>	<p>☺ The potential for participatory research to promote realistic shared expectations through mutual respect and trust should be further explored   </p>
<p>13. Different groups of people will have different perspectives on the aims and objectives of research. There will also be differences within groups. In general, lay people expect that research should make a difference to their lives.</p>	<p>☺ Strategies should be developed which link the outcomes of research more closely to the development of future services.</p> <p>☺ There should be a commitment to ensuring that research makes a difference to people's lives in a sustainable way.</p> <p>Both of these can be built in to the requirements of the funding agency, following the example of DFID. </p>
<p>14. Because of its emphasis on empowerment, participatory research is concerned with reducing inequalities.</p>	<p>☺ Participatory research approaches should be adopted in work that is aimed at reducing health inequalities. </p>
<p>15. People are often more open and willing to share knowledge with others with whom they have shared experience.</p>	<p>☺ Consideration should be given to training lay members of target groups as researchers to work with their peers.</p> <p>  </p>

Process

16. One way of breaking down language barriers is to use research techniques that rely more on visual images than spoken or written language

17. There is a tendency to use traditional survey type methods. Lay people and researchers have identified different methods of collecting data that are relevant to the needs and experiences of the target group.

18. Qualitative and quantitative methods of gathering data need not be in conflict. They can add value to each other and facilitate lay involvement.

19. There is a need for **flexibility** with regard to the direction of the research, which will evolve and change when lay people are actively involved.

20. Willingness and readiness to draw on new ideas are key indicators of success in participatory research.

☺ Researchers should consider using other research methods as alternatives or complementary to traditional survey techniques. 

☺ Where some members of a contact group are unable to attend all meetings, researchers should consider distant participation, for example via teleconferencing. 

☺ A broad concept of research, which encompasses different ways of gathering information should be adopted and incorporated in research governance documents. 

☺ Researchers should be aware that different methods of data collection can be complementary. 

☺ A dynamic and flexible approach to research should be adopted.



☺ Sponsors, funders and researchers should be aware of participatory research experiences in other fields to guide future health research. 

21. Where researchers have accepted the value of indigenous knowledge, the research has proved to be of more practical use to the group involved.

22. When lay involvement in research was effective, lay people were involved early in the process.

23. When professionals, for example funders or service providers, are not involved early in the research process, they are less likely to be committed to implementing the findings.

24. It is possible to involve lay people in ALL stages of the research process, possibly by guiding research on a project steering group.

25. It is possible to involve lay people in scientific research.

26. When research is relevant and accessible for lay people, they are more likely to be motivated to become involved.

☺ Researchers must acknowledge informal research undertaken by communities every day as being valuable. 

☺ All partners 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 in the group and they should not necessarily be 'professionals' from other fields, but rather people who may be beneficiaries of the research. 

☺ Researchers should consider the needs and motivation of specific target groups of lay people when planning projects. 

27. Different groups of people may require different ways of being engaged in research. For example some people may feel threatened by having to speak at a discussion group.

28. Some research methods can act as a barrier or incentive to participation.

29. Research can be fun. This is not to trivialise the process, but learning and development can only happen in an environment of enjoyment and motivation.

30. Participatory research emphasises a 'bottom-up' approach with a focus on locally defined priorities and local perspectives.

31. Although participatory research projects tend to be small in scale, their findings have been amalgamated to produce generalised conclusions.

☺ Researchers should aim to make meetings with lay people informal. Where possible they should take place in a location familiar to the people involved. Providing lunch, for example, can facilitate relaxed discussion and put people at ease. 

☺ An equivalent to meta-analysis should be developed to bring together the results of similar small, local projects. The World Bank has had successful experience of doing this.  

32. Where ethics committees exist, there are complex and time-consuming procedures for gaining approval for a research project, and currently only offer professionals the potential to apply, meaning that lay people wanting to instigate research require a professional sponsor.

33. Ethics committees seem concerned more with protection of individuals rather than empowerment.

☺ Consideration must be given to:

- simplifying the process of gaining ethical approval
- changing procedures 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. 💰

Resources

34. Support provided for lay people in a variety of ways, facilitated their involvement in research. Lay people saw the role of the support worker as particularly important.

☺ Researchers should provide adequate support in the following areas:

- payment of lay people for work undertaken and out of pocket expenses
- practical support in terms of transport, accessible meeting places etc
- emotional support, for example, advocacy where appropriate, good facilitation for creating, sustaining and managing relationships. 👥

35. There is a need for flexibility:

- by the funding agency to allow for changes that may occur during the research process
- in the time allowed for the research to be undertaken. When lay people are involved, more time is needed at all stages.
- about the timing and location of meetings, and a recognition of fluctuations in people's availability (due to illness, disability, caring responsibilities etc).

36. Research in some fields ends with dissemination of a research report. Often little consideration is given to ensuring that the findings are implemented and changes occur, i.e. setting up mechanisms to ensure sustainability. It is helpful if there is commitment from service providers to co-operate with the group and to realise the longer-term outcomes.

☺ Research funders should take into account the extra time and money needed when involving lay people in research and be flexible in both allowing longer lead-in time for building up relationships, and the extra expense of communicating with lay people at all stages of the research. 💰

☺ Sponsors and funders should ensure that sustainability is built in at the very start of the project, so that implications for implementation of results and on-going support are incorporated into the project design. 💰

☺ Consideration should be given to the resources required for implementing the findings of the research early in the planning process, so that research should be undertaken only if there is the capacity to act upon the findings. 💰

37. There are many implications for training:

- Facilitators should have specialist training
- lay people may require training in research methods including the use of computers for data analysis and writing reports
- training in participatory methods should be available for professionals and lay people
- professional training programmes should incorporate modules about the need for lay involvement in research; incorporating lay voices in this training can be a powerful way of giving a lay perspective.

38. Bidders for research funding often have to dress up their project proposals to suit the funding body. This, and the fierce competition between institutions for money, can mean that proposals are put forward, but cannot be carried out.

39. Value for money is not just about the lowest price.

☺ Consideration should be given to the appointment of a liaison officer within each health research and development support organisation at regional and/or local level, with special responsibility for guiding participatory research and providing support to lay people. This role would also include liaising with other agencies and groups of lay people and encourage wider dissemination of local research projects. 💰

☺ People expected to act as facilitators to participatory research should receive specialist training. 💰

☺ Participatory research approaches should be included in research methods training. 👥

☺ Training courses for health professionals should incorporate lay voices and cover ideas and methods for lay involvement in research and service development. 💰 🔑

☺ Funding bodies should build up partnerships with research institutions and groups of lay people so that bodies of expertise can grow. This would alleviate the need for proposals to be too ambitious within the given timeframe. 💰

40. Access to information is not available to all groups of people. Many databases are only available on subscription or through professional institutions.

☺ Efforts should be made to ensure that online sources of information are more widely available to the public, in accessible and easy-to-follow formats, as exemplified by the BMJ and the National Library of Medicine, through PubMed.



Recommendations for further research

- ◆ Look more specifically at the field of Overseas Development with a view to applying some of its approaches more directly to health research. For example, the Sustainable Livelihoods Approach and/or Stakeholder Analysis could be adapted for use in a health project.
- ◆ A further investigation should be carried out to discover why our searches failed to reveal many examples of research that actively involved carers. It could be that such research has been undertaken but not recorded in a way that makes it easy to find. Alternatively, it could be that research actively involving carers is not yet taking place.
- ◆ A project to further develop quality criteria for lay involvement in research should be carried out, building on some of the evaluation and assessment tools highlighted in this report.
- ◆ Evaluations of organisations that support lay people in research should be considered, in order to find out if they really do make a difference.

Finally...

Health research has the important function of developing the knowledge needed to improve health and well-being. Yet it is widely acknowledged that the considerable achievements of health research are often insufficiently followed through with implementation and integration in practice. The definition of research adopted for this scoping study indicates the value that lay people place on gaining knowledge in order to make decisions and to take action. Lessons learned from other fields indicate that ideas and methods for active lay involvement are practical and applicable to health research. Participatory approaches may help to ensure that lay people are empowered through research which can directly lead to real improvements in service provision, in the quality of care and, most importantly, in peoples' health, well-being, lives and circumstances.

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Glossary

Advocacy	Having someone ensure that lay people are able to say what they want, in the way that they want it said, to the right people at the right time.
Collaboration	In participatory research is a partnership among equals with complementary knowledge or expertise
Community	A group of people sharing a common interest – for example, cultural, social, political, health, economic interests – but not necessarily a particular geographic location
Evidence-based practice	Reference to a body of evidence or knowledge gained through research and practice about efficiency and effectiveness, to guide health and social care practitioners.
Health Action Zones	An initiative to bring together organisations within and beyond the NHS to develop and implement a locally agreed strategy for improving the health of local people. Areas designated as Health Action Zones are identified because they have a high level of poverty.
Participatory Action Research (PAR)	PAR is an approach to participatory research that emphasises ‘action for change’ as being part of the process.
Participatory Learning and Action (PLA)	PLA is an umbrella terms for a wide range of participatory research approaches (including PRA). The common theme to them all is the participation of people in the process of learning about their needs, capabilities and visions, and in the action required to address them.
Participatory Rural Appraisal (PRA)	
Partnership	Is a mutually respectful relationship based on sharing responsibilities, costs, and benefits leading to outcomes that are satisfactory to all partners
Paternalism	The attitude of a government, organisation or individual that manages the affairs of others in the ‘manner of a father’ by taking away individual responsibility and freedom of choice.
Philanthropic	Showing concern for humanity especially by performing charitable actions.
Positivism	A school of thought which saw the world as having a single reality which existed independently of the observer, and which could only be discovered by an objective and uninvolved scientist through acts of pure observation or experiment.
Quasi-experimental	A procedure which seems to be experimental, but does not exactly comply with strict experimental conditions, often undertaken because the phenomenon being studied cannot ethically or practically be studied in a more experimental way.
‘Quasi market’	A market which resembles, but is not exactly like, an open market because freedom of choice is limited in some way.
Randomised Controlled Trials (RCTs)	In RCTs, participants are randomly assigned to different interventions or treatments and the results compared with a non-intervention (control) group.
Research Assessment Exercise	An exercise that universities have to go through to secure funding by providing evidence of excellence in research, which leads to the compilation of university league tables.
Risk management	A process by which the risks of any procedure or process can be identified and minimised, often by balancing these against any potential benefits.
Stakeholders	Persons, groups or institutions who have an interest in a programme or activity because it affects them in some way
Survivor Movement	Survivor is a term by which some people experiencing mental health difficulties prefer to be known. It refers to survivors of a mental health system and survivors of difficult life experiences. The survivor movement has evolved alongside, for example, the user movement or the consumer movement.
Tokenism	The practice of making only a token effort or doing no more than the minimum requirement.
Tribalism	Loyalty by members of a group who share the same values and beliefs. Within the context of this study, it is taken to mean that the group’s exclusive loyalties deter other groups from becoming involved with them and sharing their common knowledge and language.

Databases/Webpages Searched

- ◆ PSYCINFO (subscription only – password necessary)
- ◆ MEDLINE (subscription only – password necessary)
- ◆ PUBMED (available on the Internet)
- ◆ CAREDATA (subscription only – password necessary)
- ◆ EMBASE (subscription only – password necessary)
- ◆ CINAHL (subscription only – password necessary)
- ◆ COCHRANE LIBRARY (available on the Internet)
- ◆ THE KINGS FUND DATABASE
- ◆ ELSC (ELECTRONIC LIBRARY FOR SOCIAL CARE) (available on the Internet)
- ◆ NISW (NATIONAL INSTITUTE OF SOCIAL WORK)/SSRG WEBSITE (available on the Internet)
- ◆ PARTICIPATION READING ROOM, IDS, BRIGHTON – LIBRARY DATABASE (available to anyone by appointment)
- ◆ RESOURCE CENTRE FOR PARTICIPATORY LEARNING & ACTION, IIED, LONDON – INTERNAL DATABASE (available to anyone by appointment)
- ◆ BRITISH LIBRARY OF DEVELOPMENT STUDIES, UNIVERSITY OF BRIGHTON (available on the Internet)
- ◆ JOSEPH ROWNTREE FOUNDATION – FINDINGS (available on the Internet)
- ◆ EPPI-CENTRE, SOCIAL SCIENCE RESEARCH UNIT, INSTITUTE OF EDUCATION (available on the Internet)

We also visited the websites of many organisations with research pages, which we scanned for relevant projects.

Journals Manually Searched

Because it was also possible that our key words would miss some relevant articles, key journals that we were able to access were searched manually from 1995 up until March 2001.

- ◆ CHILD AND FAMILY SOCIAL WORK
- ◆ COMMUNITY CARE – RESEARCH MATTERS
- ◆ DISABILITY & SOCIETY
- ◆ JOURNAL OF LEARNING DISABILITIES FOR NURSING, HEALTH & SOCIAL CARE
- ◆ JOURNAL OF MENTAL HEALTH UK
- ◆ MENTAL HEALTH NURSING
- ◆ PSYCHIATRIC BULLETIN

Key Words Used For Searches

POPULATION		INTERVENTION		OUTCOME
User(s)		Involvement/involved		Research
OR		OR		OR
Carer(s)		Participation		Evaluation
OR		OR		OR
Consumer(s)	AND	Collaboration	AND	Appraisal
OR		OR		OR
Lay		Partnership		Audit
		OR		
		Action		
		OR		
		(power)		

NOT

Drug, buy, advertis*, consumption, animal

Wherever possible, searches were carried out using a full combination of the keywords as above. Where this was not possible due to the nature of the database's searching methods, combinations including at least one keyword from each column were used. Some difficulties were encountered on databases where it was not possible to combine searches or when we could only search using fixed keywords on the database. For example, searching CAREDATA with the word 'user involvement', identified 919 records. Combining this with 'research' reduced the number to 144, but to manually scan through 144 records for their relevance is a very time consuming task. Every effort was made not to lose records that were potentially useful by using the 'NOT' option to reduce the number of records to a manageable number. It is possible that we missed some articles in this way, but given the timescale of the project, we could have managed this difficulty in no other way. Interestingly, most searches resulted in less than 10 records that were directly relevant to our study.

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November 2000

Dear Colleague

I have been given your name from the Swindon Users network mailing list (through The Centre for Evidence-Based Social Services (CEBSS), Exeter, who are a stakeholder in the study I am currently working on) as someone who may have an interest in this area. We are very keen to learn from others and hope you, or one of your colleagues, can help.

I am looking for examples of research projects where lay people (service users: actual or potential/carers/citizens/consumers/experts through experience) have actively influenced or controlled some or all parts of the research process. By research we mean projects which might include service monitoring, service evaluation, user-satisfaction projects or trials of effectiveness of interventions. By 'part of the research process' we mean any involvement beyond being the subject of research, e.g. helping in the design of the research or collection/analysis of data.

This is part of a national scoping study commissioned by NHS Consumers in Research intended to gather information from a broad range of sectors (including social care) and create recommendations as to how lessons learnt in other fields can be transferred to health service research. CEBSS also made a small grant to the project in order to establish a baseline of current user involvement in the South west of England. The findings of the research will develop and spread best practice within the CEBSS partnership.

I would be grateful if you have been involved in any such research, or know anyone who has, if you would take the (not much) time to fill out the attached questionnaire and return it to me in the freepost envelope provided, by 12 January 2001. Even if you are unable to answer all the questions, please complete as much as you can. If you have any questions, please do not hesitate to contact me on 01392 264660 or e-mail: l.a.thorne@exeter.ac.uk.

Thank you in advance for your time and help.

Yours faithfully

Lisa Thorne
Research Assistant

NHS SCOPING STUDY INTO LAY INVOLVEMENT IN RESEARCH

'Learning through others'

Please fill out as much as you can of the questionnaire (even if you can't answer all the questions) – any information you can provide is appreciated.

CONTACT DETAILS	
Name:	Phone No:
Organisation:	
Address:	E-mail address:

DETAILS OF RESEARCH
1. Title:
2. Please write a brief description of research aims with comments about results/conclusions if available:
3. Is the research complete or still ongoing?
4. How was the research done? E.g. surveys, face to face interviews, questionnaires, other methods (please specify).
5. Lay people had an <i>active</i> role in the following stages of the research: (please tick box(es) as appropriate)
<div style="margin-bottom: 10px;">Identifying the topics for research</div> <div style="margin-bottom: 10px;">Planning the project</div> <div style="margin-bottom: 10px;">Design – influence on methods used</div> <div style="margin-bottom: 10px;">Implementation – carrying out the research</div> <div style="margin-bottom: 10px;">Data collection</div> <div style="margin-bottom: 10px;">Analysis a) of data b) of results</div> <div style="margin-bottom: 10px;">Interpretation/Evaluation of results</div> <div style="margin-bottom: 10px;">Dissemination of results (writing articles/talking to groups etc)</div> <div style="margin-bottom: 10px;">Managing the project</div> <div style="margin-bottom: 10px;">Not sure (but more than simply being a research subject)</div>

Framework for choosing case studies – different dimensions – coded

Dimensions			
A = field of study	B = stage in research	C = degree of lay involvement	D = Research Method
A1 = Social Care	B1 = Identify Topic	C1 = Prof-led Collab	D1 = Experimental
A2 = Comm Devel UK	B2 = Planning	C2 = Collegial	D2 = Controlled observation
A3 = O/Seas Devel	B3 = Design	C3 = Community-led Collab	D3 = Structured Interview
A4 = Education	B4 = Implementation	C4 = Community-led Consult	D4 = Survey
A5 = Public Health/Health Prom	B5 = Data Collection	C5 = Community-led Contractual	D5 = Focus Group
	B6 = Analysis	C6 = Community Exclusive	D6 = Case Study
	B7 = Interpretation/evaluation		D7 = In-depth Interview
	B8 = Dissemination		D8 = Participatory method
	B9 = Management		

Categories of groups within fields (A) above:

MH = mental health
 LD = learning disability
 PD = physical disability
 YP = young people
 OP = older people
 HIV = HIV/AIDS
 EM = ethnic minority
 Pov = Low income/no car
 Home = homeless/travellers

CASE STUDY ?

Name.....

BALANCE OF BENEFIT
❖ what's been in it for you?
- to user
- institutional (provider & purchaser)
- to researcher

METHODS
(a) that enabled the partnership to happen
❖ who was involved, how did they get involved and what was their role at different stages of the research process?
(b) technical/research methods – strengths and weaknesses of those used.

CONCEPTS
• What were the ideas, thoughts and views that led to the research happening?
• What purposes, aims, outcomes were hoped for? (may be covered by write-up/report)
• Quality criteria that have emerged in this field – what has made this project a good one? - What standards would you apply to evaluate the quality of the research?
❖ Level of participation – degree of empowerment - Realistically, looking at the project overall, how much influence did you have? - Can you give me a few examples of where your involvement/lay involvement made a real difference to how the research was done?

CONTEXT
• What was it about the setting that allowed the research to be done? socio-cultural/political factors; individual factors, e.g. was there a person who made it happen & what was it about them?
• Facilitating factors and Barriers – how were barriers overcome?
❖ What resources were needed by different stakeholders that enabled the research partnership to work (e.g. time, money, training, attitude change)

HINTS/TIPS/ADVICE
OTHER OBSERVATIONS

Setting the Scene: Barrow Community Gym opened for use by mental health service users in 1998. The gym is run collaboratively, with gym users involved in all aspects of management and every day running. So it makes sense that when it came to evaluating the gym's first year, users should be an integral part of the evaluation team.

Whose idea was it and how was it funded? This project was commissioned by the North West NHS Trust and funded by the North West NHS R & D Directorate.

What did they do & how? The evaluation team, consisting of 4 gym users, 2 paid researchers and 1 staff member, was formed following two focus group meetings held to discuss how to evaluate the gym. At this point, control over the research process began to move from the professional researchers to the users themselves. Next, a questionnaire was designed and piloted by the evaluation team. This was distributed and some people were also interviewed. Users were trained to help people fill out their answers if they had any difficulties. Users collected the data, entered it on to a computer and helped with analysis. Two gym users have now **taken over the management** of the evaluation, which will continue to monitor the success of the gym every 6 months.

The research moved from **Consultative** participation, through **Active** participation when the group worked as a team until, finally, gym users took over complete **Ownership** of the evaluation.

However, not all was plain sailing...certain difficulties were encountered along the way:

There was no initial consultation with users about whether they wanted an evaluation study to be attached to the gym. Therefore recruitment for the initial focus groups was a bit of an uncertain process. Some factors influencing participation were: side effects of medication and fluctuations in mental health symptoms. The answer was to **adapt the research methods** to suit the participants.

Special Aspects of the project that made it work:

- Payment of expenses and working together over lunch.
- The level of trust users had with the research associate.
- The time and effort the research associate put into contacting users and getting them along to meetings - friendships were developed.
- Users were centrally involved from early on in the process, and therefore had a good sense of ownership over the methods and the findings.
- The researchers took the opportunity to feed back and reflect on findings with users as often as possible. The data analysis process was therefore demystified for those who were actively involved.
- Supportive funding body, willing to be flexible.

Changes that occurred because of the research and the way it was done: The evaluation process was regarded as valuable by the users involved. Generally, it led to positive changes within the gym, such as facilities being added or moved. This has made a difference to the atmosphere, making ownership/management more collaborative, and has (anecdotally) helped some users to keep up regular attendance. On a more personal level, those who were involved in the evaluation reported growth in self-confidence, having acquired new skills and increased motivation to return to college and study.

Lessons learned for researchers:

- Research should ideally build on existing skills and strengths (in this case experience of completing questionnaires, computer skills, newsletter editing). This means that the research process is introduced in bite-size chunks and is thus less alienating. It is also important to open up new potential, where possible.
- When participation is interrupted, professional-researchers should provide **continuity**. Simply being accessible to user-researchers as far as possible also helps to build confidence over time, and break down the 'professional as expert' syndrome.
- Research designs (and researchers!) should be **flexible** in accommodating user-researchers' needs and constraints in order to maximise the opportunities for participation.
- The importance of setting **supportive mechanisms** in place for user evaluation to continue after departure, and to make it clear who is responsible for what. Otherwise the venture could crumble...

And finally.....

Barrow Community Gym was launched as a Mental Health Beacon on 8 December 2000 – the one-day conference was attended by gym users, staff, the Director of the local R & D Directorate, the Minister for Health, the researchers and almost 100 other interested parties.

*To find out more about this project.....*Take a look at the University of Lancaster Department of Applied Social Science webpage. Download the full report from: <http://www.lancs.ac.uk/depts/apsocsci/gym/gymreport.pdf>

CASE STUDY 2: 'FINDING OUT'

Setting the Scene: Bristol Self Advocacy Research Group started up in 1997 as an outcome of Europe People First. Val Williams, who had already worked with the Europe People First members, was a voluntary supporter to the group at that point. People wanted to form a group that was supportive and enabled them to speak up for themselves.

Whose idea was it and how was it funded? Through their contact with this support worker, and hearing about her research, members became interested in carrying out their own research and started to think about what they might like to investigate. They decided that they would like to find out if members of other self-advocacy groups were in the same position as them and whether they faced the same difficulties. They received funding from National Lotteries Small Grants (SW), which covered travel costs and payment of the members for the interviews/discussions that they carried out.

What did they do & how? Members of the group visited other self-advocacy groups and carried out group discussions and semi-structured interviews to learn about the views of other people with learning difficulties. They discussed what self-advocacy meant to them as well as practical issues such as finding jobs and using public transport. All these meetings were recorded on cassette or videoed so that they could be analysed by the group later. After analysis, the findings were written up by members of the group in a range of formats: in a user-friendly booklet that was accessible to members of the self-advocacy groups who were consulted (Finding Out), as a chapter in a book (Ch 4, Therapy & Learning Difficulties, 1999) and in journals such as Community Care and the RCSLT Bulletin.

The research was led and owned by the Bristol Self-Advocacy Group from the start (**Ownership**). They were responsible for all the decisions made and turned to the support worker linked to the group only for encouragement or guidance. She took care to only answer questions rather than make suggestions. It is fair to say, however, that people did need to learn about research and to develop skills, an interesting process in itself, which the support worker is currently studying for her PhD.

Special Aspects of the project that made it work:

- It was fun
- The lay researchers got paid for it
- Excellent support worker
- The determination of the group

Changes that occurred because of the research and the way it was done: Members of the group increased their confidence and improved their listening and communication skills (one member has learned sign language in order to work with learning disabled children for another research project). The members of the group also feel that research is power and so through carrying out this research (and others) they have gained power in their lives and for the group through increased knowledge and shared experiences. It has also given them a sense of satisfaction and achievement, especially when people have praised their work (they have presented to other People First groups and at national conferences). They have made links with other self-advocacy groups which will be maintained as a support system and also with a view to collaborating in future research.

Lessons learned:

- With the right support, people with learning difficulties can carry out useful and reliable research
- Reports can be disseminated in many ways. E.g. the picture-based report to be sent to other groups of people with learning difficulties and the wordy chapter that was published in a book both conveyed the same messages about the work that had been done.

And finally..... One of the key members of the research team is now working part-time and has just got his level 2 NVQ Admin: he has recently received a Mencap Millennium Award for work on another project, which will provide him with the funding and a support worker to write up all the work he has done, as well as consolidate his background reading.

To find out more about this project.....

Contact Val Williams at the Norah Fry Research Centre, University of Bristol, 3 Priory Road, Bristol BS8 1TX
Val.Williams@bristol.ac.uk

CASE STUDY 3: BRIARDALE COMMUNITY CENTRE

Setting the Scene: Following community appraisals in 1999, funding was received to build a new community centre for the wards of Cowpen and Kitty Brewster, Northumberland. This is a priority area for funding and development work.

Whose idea was it and how was it funded? The local Community Association (?) wanted to be sure that the centre would offer the facilities that local people wanted and so decided to carry out a large consultation exercise. The Community Economic Development Officer for the area made the suggestion that, since local people were already intrinsically involved in the setting up of the community centre and it was their opinions that were being sought, local people should be recruited to carry out the door-to-door surveys. This was a process that she had been involved in before and had found to be successful. The Public Involvement Board of the Northumberland HAZ funded the research.

What did they do & how? 7 local people were recruited to carry out the data collection. They visited people in their homes and asked them questions from a questionnaire designed by an assistant psychologist involved in the community (and based on ideas from the future manager of the community centre). They received a day's training in which they practised asking the questions and recording answers and also discussed how they might deal with any difficult situations that could arise. The rest of the week was then spent walking the streets, knocking on doors and gathering people's opinions. The data was analysed and written up by a professional research team.

This research included active participation, but only at the stage of data collection. However, the results gave rise to a community centre that is run 100% by the community for the community.

Special Aspects of the project that made it work:

- It was fun
- It was summer and the sun was shining so it was good walking through the streets
- Providing sandwiches at lunchtime so that the local researchers got together and discussed their experiences so far that day.
- The local people involved were very accepting of each other and worked well as a team
- Supportive funding body
- Supportive partner organisations who lent resources such as clipboards
- It is possible that more people were willing to talk to the researchers because they were local people

Difficulties encountered: there were no major difficulties, but some negative aspects were:

- Most of the local researchers initially only showed an interest in the work because of the monetary reward – however, once they became involved in the training most gained a genuine interest in the project and are still in touch with the group.
- The possibility that some people refused to respond because the researchers were local people (unfortunately no record was kept of the number of refusals)

Changes that occurred because of the research and the way it was done:

The Community Centre has developed to include the most dominant ideas that came out of the survey. The local researchers learned new skills and developed confidence. A couple of them have gone on to do voluntary work and one is considering studying to go into youth work.

Lessons learned for professional researchers:

- It is important to involve people from the start – it would have been good if the local people had influenced the questions asked, instead of these being decided by professionals running the centre.
- A more cost effective service can be developed if the people who will use the service are consulted – i.e. the community centre is now busy, whereas if it had been opened offering other facilities it might not have been as popular
- Money is a good motivator

And finally..... There are plans to carry out an evaluation of the community centre annually so as to keep an eye on whether it is meeting the needs of the local people. It is hoped that local people will be employed to carry this out and also to help in the design and analysis stages of the research.

To find out more about this project.....

Contact Jean Bell, Briardale Community & Training Centre, Briardale Road, Cowpen, Blyth, Northumberland NE24 5AN

CASE STUDY 4: PRESTON ROAD ESTATE COMMUNITY PROJECT

Setting the Scene: Preston Road Estate has been identified as a Geographical Priority Area by the regeneration partnership, Hull City Vision Ltd, and was therefore chosen to be a target area within the New Deal for Communities (NDC) Pathfinder area of Hull city.

Whose idea was it and how was it funded? Kingston-upon-Hull City Council commissioned Hull DOC (Developing Our Communities) to gather local views for regeneration of the area. *Also funded by the council?*

What did they do & how? Hull DOC have a strong philosophy of involving local people as much as possible in all their projects. Therefore, a group of local people was recruited to find out what the local community felt were the problems on the estate and what needed changing in order for quality of life to improve. Local people were trained in participatory appraisal (PA) and approached members of the community on the street outside shops, at group meetings and in their homes. The information gathered was summarised by the local researchers and 4 open days were held on the estate so that any further suggestions could be added or amendments made. The final report was written by the outside researcher/supporter in conjunction with the local researchers.

The research was initiated by Hull DOC, but beyond that local people had total control over the issues raised, methods used and the people approached, making this a good example of local people having **Ownership** of a project.

Special Aspects of the project that made it work:

- PA is a method that is relaxed and there is no pressure on people to respond in any particular way...so....
- People who wouldn't usually speak up, got a chance to
- Local people talking to local people
- Not just the usual community 'activists' were involved so the results were more representative
- Great support worker/researcher
- Methods are flexible so you can involve everybody e.g. it is not necessary to be literate

Difficulties encountered: there were no major difficulties, but some negative aspects were:

- Getting the first person to commit – once one person had talked to them, others joined in
- The weather!
- Red tape/bureaucracy
- Refusals from certain groups to participate or permission to work outside or in their properties, i.e. shops

Changes that occurred because of the research and the way it was done: All the 'Next Steps' suggested in the report have been taken on by the relevant organisations. Within the community, some progress has been made with breaking apathy, people are now asking more questions and are keener to become involved. Communication between the authorities and the community has improved. PA training is not just about the methods used, but has a background philosophy of equality and shared power. The local researchers felt that the training had not only enabled them to carry out the research, but has also affected their general outlook on life. Many of the local people have gone on to be paid to carry out PA sessions for other projects. Some of the local researchers were voted by the community to be members of the NDC Board.

Lessons learned for researchers:

- When using PA, the researcher takes a step back and works more as facilitator than researcher
- PA leads to Education and Action

And finally.....As a result of this project, follow-up work is now beginning. Local people will investigate proposals for a community centre to be built on a piece of land in the estate – it is hoped that residents of the estate will shape the design of the community centre itself as well as the facilities it offers.

To find out more about this project..... contact Hull DOC, The Community Development Company Ltd, 84x12th Avenue, Hull, HU6 9LE or visit their website <http://hulldoc.demon.co.uk/ireport/report.htm>

CASE STUDY 5: HOLDERNESS YOUTH INITIATIVES

Setting the Scene: Holderness Youth Initiatives is the collective name for a number of youth councils that have formed in the Holderness and East Riding area in the last 2 or 3 years. These have developed in order to give young people the opportunity to become involved in their community and to investigate possibilities available to them.

Whose idea was it and how was it funded? All the projects are decided upon by the young people and supported by a youth worker. Funding has been received from the local council, Hull & East Riding Education Action Zone, Lloyds TSB Foundations, The Nationwide Foundation, Yorkshire & Humber Regional Development Agency and BP Sirius– each group applies for funding when they have a project they wish to take further.

What did they do & how? Having been consulted using participatory appraisal (PA) some young people wanted to carry out their own research using these methods. After training, they have been involved in many different projects, usually about local issues affecting young people. Three major pieces of work covered the issues of public transport, sexual health and crime against young people.

They have had complete **Ownership** of all the projects. The young people decided upon the issues they wanted to investigate and gathered and analysed all the information themselves.

Difficulties encountered:

- Getting support from the local community for their initiatives to be followed up. E.g. the need for a youth centre has been identified in one rural village but all proposals to use existing buildings are blocked by residents because they are concerned that young people from neighbouring villages without youth groups will be attracted and cause trouble.

Special Aspects of the project that made it work:

- PA is a very open and flexible method so there is opportunity to use it with anybody, e.g. young people attended an Age Concern conference about transport, integrated with the older people and led workshops which led to the discovery that older people and young people face the same difficulties with public transport in the Holderness and East Riding area.
- Dedicated support worker, experienced in PA and open to young people's ideas.

Changes that occurred because of the research and the way it was done:

Although each piece of work is not formally written up, they have influenced the local council through their research. They have made presentations and had a bearing on the new transport strategy and the development of a confidential service re: sexual health. As a result of another PA exercise at a local hospital, visitor identification cards have been introduced to improve security.

Confidence and literacy have improved amongst the young people and some have shown improvements in their school work.

Lessons learned for researchers:

- Young people can make a difference to policy decisions and their own lives by carrying out their own research
- Engaging with young people is not easy – the research (or conversation) must be fun and have some meaning to them, otherwise they will be easily distracted or not even become engaged in the first place.

To find out more about these projects.....contact Holderness Youth Initiatives, c/o South Holderness Youth Centre, Station Road, Preston, Hull HU12 8UZ

CASE STUDY 6: TOTNES TRAFFIC APPRAISAL WORKING GROUP

Setting the Scene: There existed a long-term problem in Totnes with traffic flow through the town. The Town Council organised a town appraisal in Autumn 1998, asking for residents' and traders' views about living in Totnes, and the traffic problem. As a result, various groups got together at a public meeting chaired by the Town Mayor in May 1999 to discuss the traffic problem. A large number of local people were there, representing different interest groups, and working groups were set up to look at things that had come out of the appraisal. One of these groups is the Totnes Traffic Appraisal Working Group.

Whose idea was it and how was it funded? Initiative came from grassroots level after the town appraisal. Funding has come from various sources including Rural Transport Forum, Shell Better Britain and the council.

What did they do & how? Early on, the group got together to try and solve some of the problems. They decided to hire an independent consultant/mediator to work with the group to keep them on track. At the first meetings the stakeholder groups (traders, councillors, local residents etc) drew together all the issues. Group members knocked on doors in the streets most likely to be affected by town centre traffic, left leaflets and flyers, and talked to people in the High Street. They also visited local schools, and groups of disabled people. By August 2000, 220 issues had been identified, sorted and categorised. Issues were changed to 'needs' and divided into 'contentious' and 'non-contentious' categories. The 'contentious' issues were discussed and 20 proposals were made which were whittled down to 10. The proposals have been put together with a portfolio of other documentation and placed in the local library for people to view and comment on. The 10 proposals were considered at a stakeholders' meeting in April 2001, but no overall conclusion was reached.

The people on the Appraisal Group have complete **Ownership** of the project. It has been considered a truly 'bottom-up' approach, instigated by local people and facilitated by the local councils. However, there are a large number of stakeholders, and a lay person who accompanied the researcher to the stakeholders' meeting in April noted that one or two stakeholders she spoke to felt they had little influence and were cynical about the potential outcomes, whereas others were more positive.

Difficulties encountered along the way:

- Getting funding to continue the process. The mediator was paid to April 2001, but there is no more funding at present to further the work, other than the unpaid efforts of the group.
- It has been a long process. Some people now want faster solutions, but the indications are that any proposals put forward won't be considered by the council until at least next year (2002).

Special Aspects of the project that are making it work:

- The people in the group - everyone willing to work together, help & care for each other, working towards a solution rather than arguing over the various issues
- Complementary skills of group members e.g. fund-raising, publicity etc
- Willingness of the group to use their own homes and own equipment and to do the work in their own time.
- Commitment of the local authorities to co-operate with the group and participate in discussions. There is a longer term commitment to realise the outcomes

Changes that occurred because of the research and the way it was done (so far): People from the different stakeholder groups have been able to work together towards solutions. Barriers have been broken down between groups that have been in conflict for years. Proposals to solve the non-contentious issues have been taken to the relevant organisations and authorities. It has been possible to reach an agreement on potential solutions to the contentious issues, the most popular of which will hopefully be accepted by local authorities who have made a commitment to the project.

Lessons learned for researchers:

- It's not always necessary to have a group constitution. The aim was to keep it simple 'why do you need a constitution?'
- The importance of keeping politics out of the discussion and focus on the objectives

And finally.....

It is not known what will happen after the next stakeholder meeting on 30 April. There is no more funding to pay the mediator, although there may still be issues that need discussing. It may be necessary to hand over to the local authority, though the stakeholders would like to further retain ownership

To find out more about this project..... contact Robin Willis-Fleming on 01803 867774

"what is fantastic about the process is that it is completely community-led, and has gone beyond the people themselves" (member of working group)

CASE STUDY 7: BARRIERS TO INDEPENDENCE

Setting the Scene: Help And Care is a voluntary organisation that has been supporting older people in Bournemouth for the last fifteen years by providing a comprehensive range of services and undertaking research.

Whose idea was it and how was it funded? Further to discussions with Social Services, following anecdotal evidence about barriers to independence for older people, a proposal was put together. Social Services agreed to commission and fund the project. This provided Help And Care with the money to employ a research assistant to lead the project.

What did they do & how? A group of 14 older people were recruited to form an advisory group on the project. An initial research question; what barriers to independence do older people face? had been proposed, but this has now been reshaped according to the factors that the older people themselves saw as important within that question. They have met once a month since November 2000 and are now at the stage where they have decided on the research methods they will use. The group has chosen to use a structured interview with individual older people and with focus groups. At their next meeting they will work on designing the interview schedule, questions for which they have already discussed. They are now preparing to receive training in interview techniques so that they can go out and do the fieldwork themselves. They also plan to analyse the data with the support of the research assistant and disseminate their findings to interested organisations as well as the commissioning body, social services.

This research was initiated by Help And Care, who proposed the initial research question and obtained the funding, but from the point that they were recruited, the older people's group has had **Ownership** of the project and shaped the progress of the project.

Special Aspects of the project that made it work:

- Supportive funding body – open to changes in the research proposal
- Enthusiastic group of older people
- Good cross-section of older people recruited (through considerable work by research assistant)
- Fantastic research assistant to facilitate meetings and make sure that everyone's voice is heard

Difficulties encountered:

- Time – the project is already behind the planned schedule, but the funder is understanding about this
 - recruitment of older people took longer than expected
- Trying to recruit older people from ethnic minority groups was difficult. Islamic and Asian communities felt that there would be a language problem and were against working with social services as they believe that they should look after their own elderly.
- Access to information: had to rely on friends in social services to get access to electronic databases.
: the research assistant was able to join the university library but was not able to access electronic databases there, only handsearching of journals possible.
- Access to software packages for analysing data – it may be possible to use a computer at social services

Changes that occurred because of the research and the way it was done: Although the research project is not yet in full swing, Help And Care has already benefited from starting communications with different communities, e.g. ethnic minority and lesbian/gay groups.

Lessons learned for professional researchers:

- It is important to plan extra time for involving older people in research.
- It is important to consider that many people over 70 years old may have left school aged 14 and therefore have difficulty with form filling and may also require extra support for discussion of research methods and the research question.
- Confidence building is an important part of preparation for lay researchers

And finally.....

The group of older people are already gaining in confidence, getting on really well together and made new social contacts.

To find out more about this project..... Contact Help And Care, 896 Christchurch Road, Bournemouth, Dorset BH7 6DL

"It's no good designing a broom for a road sweeper, if you don't ask him first how he sweeps the road."
(research group member on the need for older people to research older people's issues)

CASE STUDY 8: ALTERNATIVE CHOICES, CAMDEN

Setting the Scene: The *Strategies for Living* Project was initially a 3-year UK-wide Mental Health Foundation project funded by the National Lottery Charities Board, investigating coping strategies used by people experiencing mental distress. In addition, the Project gave small grants, training and support to six local projects, one of which took place in Camden, London.

Whose idea was it and how was it funded? A member of Camden Mental Health Consortium, a mental health service user/ex-user/survivor organisation, was concerned about lack of information locally. Together with another Camden Consortium member, he was particularly interested in 'alternative' strategies for coping with mental distress. Work on '*Choices: A Mental Health Handbook for Camden*' had already begun when the project linked in with the *Strategies for Living* Project who provided support for their '*Alternative Choices*' investigation into alternatives to mainstream mental health services that local people might use or be interested in.

The project was initiated and carried out by people in Camden with experience of using mental health services. Although supported by *Strategies for Living*, local service users and ex-users had **Ownership** of the project.

What did they do & how? Public meetings, involving service users and professionals, were held to discuss both the handbook and *Alternative Choices* research. Flyers were sent out via local networks, hospitals, health centres, day centres and other statutory/voluntary sector organisations. From these, and smaller meetings with mental health service users in hospitals and day centres, key themes were developed, and discussion/focus groups of service users later looked at three broad themes: alternative/complementary therapies, self-help approaches, and religious/spiritual beliefs and practices. People's experiences of these approaches, their benefits and disadvantages, and their availability in the local area were discussed.

Difficulties encountered along the way:

- Hard work for the lay researchers (working from home and in their own time)
- Money (lack of funding for equipment or office space). Need for extra administrative support and resources.
- Finding time to finish the project: writing a report when employed in a new job has proved extremely difficult.
- Some people dropped out of meetings that they had said they would attend – this was frustrating as numbers were limited and sometimes others who would have attended were turned down.
- Recruiting diverse enough groups of people for some discussions, e.g. the focus groups on religion and spirituality; although a range of *current* beliefs and practices were evident, everybody involved was originally from a Christian or Jewish background; people from other faith groups were not represented.

Special Aspects of the project that made it work:

- Carried out by and with people with experience of mental distress/using mental health services - people were open with each other and willing to share their knowledge and experiences.
- Mutual learning, exchange of information – a two way process.
- A good cross-section of people became involved generally - meetings were advertised in ordinary language, aiming to include everyone rather than employing technical language, jargon or alienating terms.
- A strong network of interested people already existed in Camden so the project was able to build on this.

Changes that occurred because of the research and the way it was done:

A handbook of information services and support options for people facing mental distress in Camden has been published. It is a local guide, but contains ideas that could be utilised by other localities. The handbook has been received enthusiastically. There is some evidence of a move towards more 'alternative choices' in mental health services (e.g. development of a crisis house as an alternative to hospitalisation). Some *Alternative Choices* participants have been involved in these developments. New relationships and networks have been established.

Lessons learned:

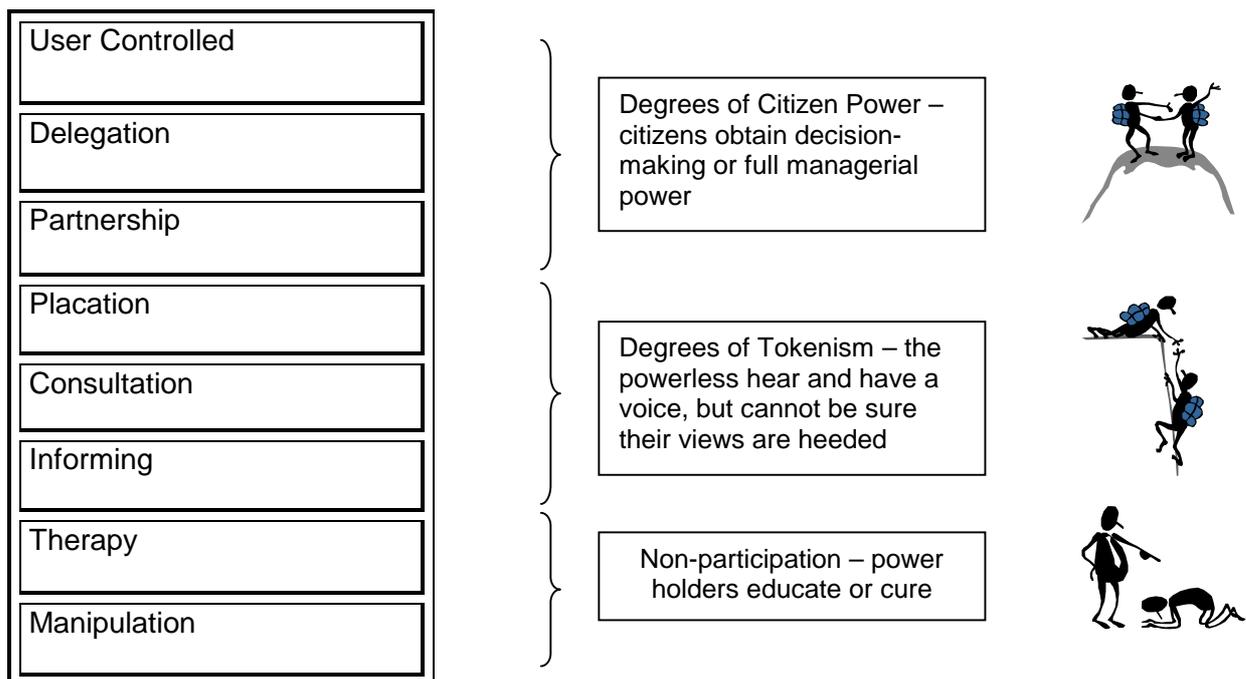
- The importance of local knowledge, knowing the geographical area that is being researched, i.e. taking the time to build relationships and make contacts so that as many people as possible can become involved.
- The importance of working to realistic proposals and aims, i.e. not taking on too much in too short a time.
- The importance of working with support from well-resourced, professionally-run organisations locally, and offering something that professionals and service users find useful - this has included providing information about alternatives that people may be willing to accept/learn from.

And finally.....It is hoped that funding will be obtained to update The Choices handbook in the future, and that a final report on *Alternative Choices* (the *Strategies for Living* supported research) will be in circulation soon.

To find out more about this project..... contact: Vicky Nicholls, Strategies for Living, MHF, 20-21 Cornwall Terrace, London NW1 4QL, or Yan Weaver, 1st Floor, 48 Fortess Road, Kentish Town, London NW5 2HG

About the handbook: "*It's indispensable!*" (Day Centre Manager) "*a mine of information*" (Service User)

Figure 1 - Ladder of Citizen Partnership



(Source: Arnstein, SR (1969), Journal of the American Institute of Planners Vol 35 pp216-224)

Figure 2 - Participation, Involvement and Research

Mode of Participation	Nature of user involvement	Relationship between researchers and users
Co-option	Tokenism: representatives are chosen, but no real action	On
Compliance	Tasks are assigned, with incentives; researchers decide agenda and direct the process	For
Consultation	Users' opinions asked, researchers analyse and decide on a course of action	For/with
Co-operation	Users work together with researchers to determine priorities ; responsibility remains with researchers for direction the process	With
Co-learning	Users and researchers share their knowledge to create new understanding and work together to form action plans with researcher facilitation	With/by
Collective Action	Users set their own agenda and mobilise to carry it out, in the absence of outside researchers or facilitators	By

(Source: Adapted from Cornwall, A. in de Koning & Martin, Participatory Research in Health. London: Zed Books. 1996)