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TECHNICAL
REPORT

Participatory Health Research

International Observatory on Health Research Systems

Sharif Ismail

Prepared as part of RAND Europe's Health Research System Observatory,
funded by the UK Department of Health

RAND EUROPE

The research described in this report was prepared for the UK Department of Health.

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Preface

This document is a thematic report that provides an overview of public participation in health research. The report complements other briefings produced under the Observatory on Health Research Systems currently being developed by RAND Europe. The research for the report was conducted with funding support from the Health Research and Development Policy Research Unit of the English Department of Health.

The purpose of the document is to provide non-specialists with an overview of the evolution and development of participatory health research across a range of economically developed countries. The report is divided broadly into two parts. The first part addresses the rationale for involving lay participants in health research in the first place, and explores some of the drivers underpinning recent moves to bolster participatory research methods. It also highlights some of the advantages and disadvantages of participatory approaches. The second part includes a series of country case studies, covering current patient and service-user involvement practices in Australia, Canada, the Netherlands, the United Kingdom, and the United States. The report concludes with a review of some options available to policymakers looking to boost or improve current practices, and an outline of further research needs.

On the basis of desk research, the report highlights key areas of consensus but also areas of ongoing debate. It does not seek to be exhaustive; the range of practices in this large and growing field of research is extensive and readers are pointed to more comprehensive sources on particular aspects of patient and service-user involvement at various points in the report.

The report will be of interest to government officials dealing with health research policy, medical research councils, health research charities, institutions hosting health research projects, researchers, and patients and service users themselves.

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Summary

- The language of participatory research is now prevalent within the health research field and beyond, even though this approach emerged in the very late 20th century.
- Initially stimulated by long-term processes of historical and social change in developed countries, participatory research has been driven lately by the emergence of powerful new actors in civil society—some of them social movements (including the feminist movement), others formal organisations (i.e. AIDS campaigning organisations), and, in a small number of cases, individual activists (e.g. Brown et al., 2004). It has been associated with parallel changes in the status of patients, who are increasingly regarded as active participants in defining the care they receive, rather than passive recipients.
- But participatory research has also been underpinned by powerful arguments grounded in moral and political philosophy. Some simply assert the ethical importance of involving lay participants in the governance of health research projects, rather than as mere subjects. Others envisage a much more holistic approach, advocating the democratisation of a scientific research establishment that they argue has come to be viewed with an increasing level of distrust by the general public.
- This complex range of drivers and precipitating factors has helped to bring about quite varied approaches to participatory research. There is no consensus on who may be included within the broad term of "patient and service-user"; participatory research may involve anyone from patients through to representatives (activists, carers, etc.), and even civil society organisations acting on the behalf of patients. Involvement may also be of varying degrees: at a minimal level, lay participants may simply be approached through the standard route of consultations, but there are also instances in which they have directly controlled or even led research projects.
- Although there are important practical arguments for participatory research (but also some notable ones against), our understanding of the strengths and weaknesses of this approach is hampered by ongoing disagreement over the terms on which they should be judged, and a lack of clear evidence. On the one hand, anecdotal reports suggest that participatory methods may improve both the quality of research and the quality of the health interventions that are developed

as a result. Some contend that these methods help to improve relations between researchers and ordinary citizens, particularly by building an understanding of the technical issues relating to research among members of the community. Others suggest that participatory approaches have helped to overcome long-term problems of under-representation for marginalised groups, and promoted greater understanding of the proper ethical conduct of health research. On the other hand, detractors accuse it of reducing the effectiveness of research by pretending to be representative of wider communities when this is in fact impossible, thus damaging the quality of research by introducing into the process participants with little understanding of the underlying science and by introducing systematic biases that may skew research findings. Ultimately, however, participatory research should be acknowledged as an exercise in trade-offs, and costs resulting from skewing effects must be balanced against the benefits of improved validity and research question definition, among others.

- We find evidence of a range of experiences internationally, most of which are focused on issues in mental health and social medicine. Importantly, the evolution of participatory research has varied from country to country, sometimes reflecting particular institutional histories (e.g. strong centralisation of health-care provision in the United Kingdom), or growing concern for the rights of marginalised or disenfranchised communities (e.g. aboriginals in Australia and Canada). The Netherlands is an unusual case. Here, participatory approaches seem to have been entrenched since the early 1970s through science shops, linking universities with their surrounding communities in a bottom-up way; this is a model that is now winning wider support with financial backing from the European Union.
- Although there seems to be no question that participatory research is here to stay, getting the most out of this approach to health research in future will require further attention in a number of areas. We need a better understanding of how to evaluate participatory research, and measure outcomes relating to it. We can nevertheless draw some conclusions about strengthening it; there is, for example, some evidence that participatory research is more successful when researchers and lay participants are trained in preparation, before projects begin; training procedures are stronger in some areas than others. Finally, there is a clear need for further evidence on what works with respect to participatory research. Much of what is known about the success or otherwise of patient and service-user involvement derives from one-off case studies or anecdotal evidence, and greater clarity will be needed if we are to ensure successful outcomes in future.

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Abbreviations and terms

10/90 gap	The allocation of 90% of the world's health research resources to meeting the needs of 10% of the world's population
AMRC	Association of Medical Research Charities
CBPR	community-based participatory research
CIHR	Canadian Institutes of Health Research
COPR	Council of Public Representatives
CSOs	civil society organisations
NHMRC	National Health and Medical Research Council of Australia
NHS	National Health Service
NIH	National Institutes of Health
ZonMw	Netherlands Organisation for Health Research and Development

CHAPTER 1 Introduction

“Participatory research” describes a range of approaches by which lay individuals or groups are involved in scientific research. There is no universally agreed definition of this term; research may involve anyone from patients through to representatives (activists, carers, etc.), and even civil society organisations acting on the behalf of patients. Involvement may also be of varying degrees: at a minimal level, lay participants may simply be approached through the standard route of consultations, but there are also instances in which they have directly controlled or even led research projects.

Public involvement in health research has been an emerging phenomenon in many economically developed countries over the past 10–15 years. The drivers for this change are many and varied, but processes of social change since the 1960s that have favoured individual empowerment, and what might be called the democratisation of scientific research, have played their part. It is increasingly the case that research funding bodies—public and non-profit—demand evidence of lay participation in proposed projects as a condition for the award of funding.

1.1 Aims and objectives of the report

The research for this document was supported by the Health Research and Development Policy Research Unit of the English Department of Health as part of the Health Research Observatory currently being put in place by RAND Europe. The purpose of the document is to:

- Provide non-specialists with an overview of the evolution and development of participatory health research across a range of economically developed countries.
- Highlights key areas of consensus.
- Explore some of the critiques of existing approaches to participatory research in the health field, and suggest some ways in which these might be rectified.

The report does not seek to be exhaustive. The range of practices in this large and growing field of research is extensive and readers are pointed to more comprehensive sources on particular aspects of patient and service-user involvement at various points throughout.

We anticipate that the report will be of interest to government officials dealing with health research policy, medical research councils, health research charities, institutions hosting health research projects, researchers, and patients and service users themselves.

1.2 Study approach and methodology

The report is based on a review of the available literature on this topic. The review is not intended to be a systematic one, but a narrative review that is based on a structured approach to the literature on this topic. Search strategies were developed using a range of related key words and phrases (including "participatory research", "community-based participatory research", "collaborative research", "lay participation" and so forth), and run through well-recognised databases and search engines such as NCBI. Other relevant sources were suggested to the author by advisers to the project where relevant. No time limit was imposed in terms of the age of the sources used, although in practice the narrative relies most heavily on texts that have been published in the past 10-15 years.

1.3 Structure of the report

The report is structured around headings and themes designed to provide an easily navigable introduction to this complex area. It is divided into two parts. The first part explores the rationale that underpins lay participation in health research and introduces the reader to some of the drivers that have promoted its spread, in three chapters. The first chapter explores varying understandings of participatory research in the United Kingdom and internationally, with a focus on definitions and levels of involvement in health research projects. It also discusses lay involvement in processes of strategic decisionmaking, including the prioritisation of health research issues and funding decisions. The second chapter looks at underlying drivers of the move towards participatory health research. It focuses on long-term historical and social change, and some of the philosophical arguments that have been advanced in favour of increased lay participation in health research, before identifying some of the key players in this change. The third chapter looks at related, but more applied, issues of research practice. It addresses some of the advantages and disadvantages of participatory approaches, and identifies some wider issues that need to be considered by research policymakers when assessing feasibility of this kind of research.

The second part looks at international experiences of participatory research—in Australia, Canada, the Netherlands, the United Kingdom, and the United States. The aim is to identify how the evolution of participatory research has differed from country to country, to explore possible factors underlying these differences, and to identify promising or unusual practices of potential interest. This part concludes with a brief overview of lessons from participatory research experiences in developing countries.

The report ends with a short chapter that identifies some themes that cut across the preceding discussion. This is used as the basis for suggesting some possible areas of focus for policymakers and research funders in the future.

CHAPTER 2 What is participatory health research?

Headline points:

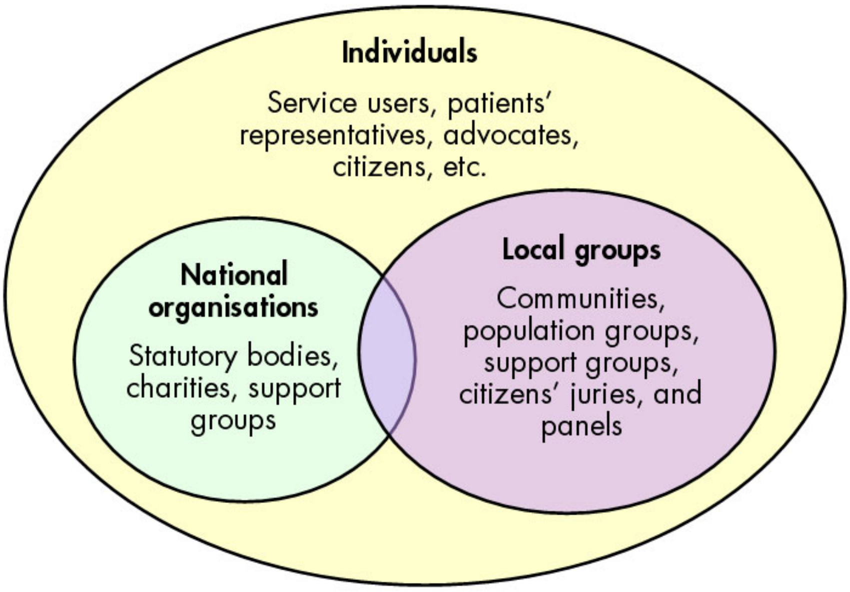
- The spectrum of approaches to participatory health research is broad.
- "Participants" may include individuals, local groups or even organisations
- Participation may range from involvement in process-level activities in individual research projects to strategic-level involvement in decision-making (e.g. funding)
- Important considerations when determining how best to involve lay participants in research include the type of knowledge that is sought (particularly whether it is to have general applicability, or focuses instead on specific populations and groups) and the level at which participants are involved – in research processes or strategic decision-making.
- There are a growing number of mechanisms for supporting participation within this broader framework.

The spectrum of potential forms of participatory health research is broad. Although there is a large and growing body of literature relating to participation in general, there remains a great deal of disagreement as to how it should be defined. Indeed, some have argued that participation is an "essentially contested concept" (Davies, 1999). This chapter attempts to make sense of the variety of forms that participation may take.

2.1 Who participates?

First, there is the question of who is involved. Box 2.1 contains some widely accepted definitions for the terms most commonly used to describe participants in health research. The tension between definitions that focus on the individual, as opposed to the group, is an important one, and an area in which—as we shall see—there remains some disagreement.

The language used to describe individual participants varies substantially in the literature, where terms including "patient", "service user", "lay participant", and "client" have been used. Whereas some of the definitions in Box 2.1 help to bring out some of the key distinctions between these terms, the choice of which one to use is often influenced by the context in which the research takes place, and is ultimately negotiated with the participants themselves. In some instances, for example, the term "customer" has been rejected as implying a view of the health research world that is too market oriented. Similarly, the term "user" has been rejected on occasions because of perceived associations with substance misuse. The term "consumer" is often viewed as a useful middle-ground option (Boote, Telford, and Cooper, 2002).


Individuals
Service users, patients' representatives, advocates, citizens, etc.
National organisations
Statutory bodies, charities, support groups
Local groups
Communities, population groups, support groups, citizens' juries, and panels

SOURCE: Adapted from Boote, Barber, and Cooper, 2002.

Figure 2.1—Identifying who is involved in participatory health research

Whereas individual patients and service users may participate in health research in their own right or act as representatives for their wider community, they are also occasionally represented by other, informed individuals or groups in research processes. For example, lobby groups, patient activists, and even pressure groups may be involved in helping to define the research question or steer the research in particular directions once it is underway on behalf of individual patients and service users (Oliver et al., 2004). Similarly, it is increasingly common for those with a close understanding of patient and service-user issues (e.g. carers for those with long-term illnesses) to be involved in research projects as external advisers. Civil society organisations (CSOs) also appear to be playing an increasingly important part in directing the research process, whether through direct involvement or external pressure.[2] As we shall see in due course, this is increasingly the case in the developing world and indeed is actively encouraged by some international organisations working in this area (Sanders et al., 2004; Tindana et al., 2007).

---

[2] Since we refer to CSOs mainly in the context of developing countries in this report, we follow the UK Department for International Development's definition of these organisations as those that, "work in an arena between the household, the private sector and the state to negotiate matters of public concern". See the Department's Web site: http://www.dfid.gov.uk/aboutdfid/DFIDwork/workwithcs/cs-how-to-work-definition.asp (as of Sept 4, 2008). These organisations may include a range of non-governmental organisations, faith-based organisations, community groups, professional associations and syndicates, trade unions, media organisations, think tanks, etc.

Patient—A narrow definition of the participants in health research, including only those who are in receipt of hospital care.

Service user—A wider definition of the participants in health research, including patients and potential patients; long-term users of services; carers and parents; and potentially a wider cross-section of society with limited or occasional contact with the health system.

Consumer—A useful catch-all term that may include patients and potential patients; long-term users of services; carers and parents; organisations that represent consumers' interests; members of the public who are the targets of health promotion campaigns; and campaign groups driving research in particular directions in response to identified needs (Oliver et al., 2004)

Lay participant—Non-specialist (i.e. non-researcher) member of the public, involved in the research process. In theory, a lay participant could come from any of the groups identified in the definition of consumer above.

Community-based research—A collaborative approach that involves community members, organisational representatives and researchers equitably in all aspects of the research process. It brings together a class of methods, including participatory action research; action research; cooperative inquiry; and participatory evaluation (of health technologies and so forth) (Israel et al., 1998). The key common feature of all these approaches is an explicit commitment to conducting research that will benefit the participants through direct intervention or the use of results to effect wider change.

Box 2.1—Some commonly used terms to describe participatory health research

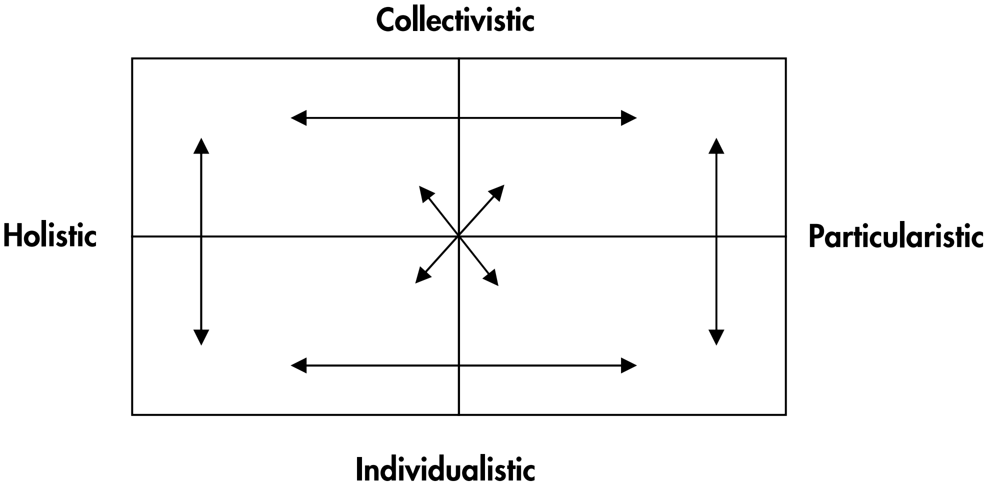
There are no hard and fast rules governing who participates in individual research projects. The central requirement of those involved in participatory research has tended to be that they have some experiential understanding—whether direct or indirect—of the illness, disease, or area of health research under investigation (Oliver *et al.*, 2004). But this should not be regarded as a pre-condition. For new areas of research, such as therapeutic cloning for example, it would be unrealistic to expect lay participants to have 'experiential understanding' *before* the beginning of a particular project. On the contrary, this is likely to develop only through participation in the research. There may be considerable value in discussing the potential implications and consequences of new and controversial areas of research with lay participants even if they do not have experiential understanding. This broadly defined response to the question of 'who participates?' helps to explain how participatory research comes to have embraced such a wide range of methods and approaches.

2.2 How are lay participants involved?

Different approaches to the question of "who participates" are also reflected in the way in which lay participants are then integrated into the research process. The way in which lay participants are involved very often depends on the specific *kind* of knowledge that the research process is designed to generate. We can also usefully make a distinction between higher order, strategic involvement, and lower order, process-level involvement – a distinction that structures the discussion of the strengths and weaknesses of participatory research that follows.

2.2.1 Understanding what kind of knowledge is sought

Early conceptual understandings of participation tended to categorise it in terms of an ascending hierarchy, ranging from manipulation, through informing, consulting and placating, to partnership, delegation and in the most advanced cases, citizen control (Arnstein, 1969). This model has been challenged in recent years, because it was unclear whether it adequately captured the variety of approaches that might be taken to generating knowledge from research.



SOURCE: Adapted from Khan, 1999.

Figure 2.2—The Public Involvement Matrix.

An alternative, matrix-based model has been proposed by Khan (1999). This model situates different approaches to public participation along two axes, one ranging from individual to collective participation, and the other from holistic to particularistic. The spectrum from collectivistic to individual participation captures the choice about whether everyone who is likely to be affected by the issue in question participates in the research, or whether individuals choose to participate based on personal interest or the type of services they want. The spectrum from holistic to particularistic captures the choice between the *kind of knowledge* that is sought from the research project – i.e. whether this knowledge can be applied to the larger, common good (holistic), or whether it refers more to particularistic needs and interests.

2.2.2 The nature of involvement: strategy or process?

Strategic involvement brings patients and service users into the process of research policymaking and funding allocation (Kuruvilla, 2005). This concerns not only decisions made within countries, but also—although to a much lesser extent at present—decisions on strategic issues that cut across national borders (international health research governance, funding allocation, etc.).

Although a relatively unusual practice internationally at present, there are a growing number of examples of patients and service users being consulted by research funding bodies to help decide on research priorities at national, regional, or local levels, on the basis of issues such as relevance, acceptability, costs, equity implications, etc. The U.S. National Institutes of Health (NIH) has integrated community members into its decisionmaking processes through the creation of an advisory body: the Director's Council of Public Representatives (COPR; see the case study below for further details).[3] In the United Kingdom, the National Institute for Health and Clinical Excellence has involved community members in helping to develop some of its guidance, especially in the area of behaviour change.[4] There are also examples of this kind of involvement in governing asthma research in the Netherlands (Caron-Flinterman et al., 2006).

Case study—Lay participation in strategic decisionmaking at the NIH

The Director's COPR was established at the NIH in 1998 in response to a report released by the Institute of Medicine calling for greater public participation in the process of decisionmaking at health research funding bodies in the United States. It contains 21 members, each of which are appointed by the director of the NIH. Members are chosen through a nationwide application process to serve for up to three years on the council, and because of the high number of applications received, the NIH also runs an associate programme to maintain contact with highly qualified individuals who might be eligible for nomination in the future. The range of individuals involved is substantial—they may be patients, family members of patients, health-care professionals, scientists, health and science communicators (e.g. journalists), and those involved in education.

The activities of the COPR are varied. Members judge consumer-oriented material produced by the NIH to communicate the work that it does. They are also invited to comment on strategic plans, guidelines, Web sites, and other forms of communication, as well as sit on NIH panels, and are occasionally involved in workgroups. On this basis, it provides advice to the Director of the NIH on policy and research issues.

Although the COPR is advisory, various sources suggest that in fact it has considerable authority (Avalere Health, 2007). It may seek external advice from appropriately qualified consultants to assist in its decisionmaking.

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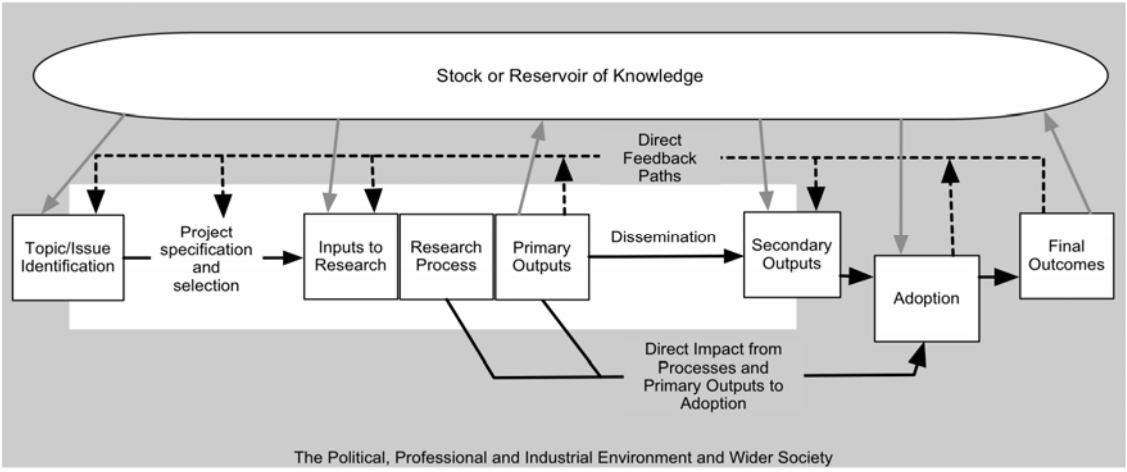
[3] COPR Web site: http://copr.nih.gov/.

[4] National Institute for Health and Clinical Excellence, "Knowledge, Attitude and Behaviour Change Guidance – Lay Members 'Job Description' (Form A)," http://www.nice.org.uk/guidance/index.jsp?action=download&o=34628 (as of September 4, 2008).

Patients and service users also participate as members of peer-review panels in the decisionmaking on which research proposals to fund (O'Donnell and Entwistle, 2004a). This model is increasingly favoured by so-called third-sector funding bodies.[5] A survey carried out by the Association of Medical Research Charities (AMRC) in the United Kingdom in 2006, for example, found that 53% of its member organisations involved community members in their review process at some level (AMRC, 2006).

At the international level, resource allocation is an issue of major concern in developing countries, where the so-called "10/90 gap" (describing the allocation of 90% of the world's health research resources to meeting the needs of 10% of the world's population) is widely acknowledged (Sanders et al., 2004). Consumers in the developing world, usually through the medium of CSOs, may have an important role in pushing for change on resource allocation issues, given sufficient access to the policy-making process (Bhan et al., 2007). However, CSOs usually force access through lobbying or campaigning, rather than by being formally included in strategic decisionmaking processes.


Stock or Reservoir of Knowledge
Direct Feedback Paths
Topic/Issue Identification
Project specification and selection
Inputs to Research
Research Process
Primary Outputs
Dissemination
Secondary Outputs
Adoption
Final Outcomes
Direct Impact from Processes and Primary Outputs to Adoption
The Political, Professional and Industrial Environment and Wider Society

SOURCE: Adapted from Wooding *et al.,* 2004.

Figure 2.3 – the Payback Model provides a useful description of key stages and interfaces in the research process.

Overall, process-level involvement is a more common model for patient and service-user involvement in health research (Oliver et al., 2004). To better understand the form this involvement takes, it may be instructive to view the process of scientific research in terms of a logic model, involving inputs (problem formulation, funding, researcher expertise, etc.), process (the activity of research), and outputs (research findings and the full spectrum of outputs and outcomes, including the implementation of research findings). A sample model of this kind is illustrated in figure 2.3. At the input level, patients and service users may be involved in defining the research question or designing research projects. Patients and service users may be involved directly in the process of research as informed participants in the research itself, or helping to conduct it. This is true of the large number of clinical trials that are conducted each year to support therapeutic developments. Finally, they may be involved in processing, disseminating, and encouraging the implementation of the results of research: the output stage. In many instances, patients and service users are involved in more than one of these stages in the research process; in some cases, they are involved throughout.

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[5] The UK government defines the "third sector" as including those non-governmental organisations that, "are value-driven and which principally reinvest their surpluses to further social, environmental or cultural objectives". This definition includes voluntary and community organisations, social enterprises, cooperatives, and mutual organisations (HM Treasury, 2007).

2.2.3 The form of involvement: mechanisms of participation

There are a great number of possible mechanisms for participation in health research, depending on the outcomes that are sought. Table 2.1 provides some indication of the range of methods normally considered – though it is not comprehensive.

At a minimal level, patient and service-user involvement may be little more than tokenistic. This may occur purely to satisfy the requirements of research ethics committees or funding bodies (Boote, Telford, and Cooper, 2002). It may also come about as a response to concerted consumer action against a dominant view within the research community; this was certainly the case, for example, in the early days of AIDS research (Epstein, 1996).

Most participatory research projects fall into the second category of consultative engagement (Boote, Telford, and Cooper, 2002). Consultative approaches are by far the most common when it comes to involving lay people in strategic decisionmaking. The NIH's COPR is an important example. In the United Kingdom, Kidney Research UK involves lay participants in the review process as members of the grant-making panel, but they have no formal voting rights. Instead, they are party to all the information that other members of the panel have access to, and may contribute to discussions on each individual proposal (AMRC, 2006).

Consultation is also the most common approach to process-level involvement of lay participants in health research. Whereas researchers continue to have a directing role in formulating research questions and designing the methods, they may consult with patients and service users throughout the process to help refine it. Common forms of consultation include the holding of one-off meetings and focus groups to help formulate the research question, or simply writing to patients and service users to invite their views on a particular research proposal (Oliver et al., 2004). In most cases, consultation occurs only at the research formulation stage; once consumer views have been gathered and incorporated into the problem formulation and design, researchers pursue their work without further external engagement. Examples of this approach to involvement in research are manifold and include a United Kingdom-based consultation exercise to gather the views of consumers on priorities for National Health Service (NHS) research in the North Thames (London) area. The researchers in this exercise consulted a broad range of organisations, including those representing ethnic and other minority groups to produce a series of recommendations that were carried in the final report. However, the impact of these recommendations is unclear (Oliver et al., 2004).

Table 2.1
Some of the formal mechanisms for integrating lay participants into strategic- and/or process-level decisionmaking on health research

Mechanism	Strategic or process level?	Degree of participation? (min. to max.)	Sample form and size?	Time scale and duration?	Characteristics?
Referendum	Strategic	Tokenistic to consultative	Potentially, entire population; realistically, smaller sample	Vote cast at single point in time	Vote usually on one of two options. Each vote carries equal weight
Public hearing/inquiry	Strategic	Tokenistic to consultative	Interested citizens	May last weeks, months, or years	Presentations of evidence in open form
Public opinion survey	Strategic	Tokenistic to consultative	Large sample, representative of relevant population segments	Single event, lasting no more than a few minutes	Written questionnaire or phone survey
Focus group	Strategic or process	Tokenistic to consultative	Small group of 5–12, selected to be representative	Single meeting of up to 2 hours	Free discussion on general topic with limited input from facilitator
Citizen's jury/panel	Strategic	Tokenistic to consultative	12–20 people selected to be representative of the local population	Meetings over several days (not precise)	Lay panel with independent facilitator questioning experts
Review panel membership	Strategic	Tokenistic to consultative or collaborative	Usually small number (2–3) selected to be representative	Meetings on several occasions over the year	Review of research grant applications with researchers and funding managers

SOURCE: Adapted from Rowe and Frewer, 2000.

Collaboration is a more integrative form of involvement. It entails active and ongoing engagement with patients and service users throughout the research process, from problem formulation to research execution, and finally to dissemination and sometimes implementation of findings (Oliver et al., 2004). From a strategic perspective, examples of a truly collaborative approach to decisionmaking by health research bodies are relatively rare. The Parkinson's Disease Society in the United Kingdom is an important exception. Members of its 45-strong research network of volunteers who either have Parkinson's disease themselves or have relatives with the disease, are involved in everything from assessing and evaluating reports on specific grants to reviewing fast-track proposals and even carrying out site visits (AMRC, 2006). At the process level, patients and service users may be involved as members of research committees, or as participants in the research itself. The UK National Programme on New and Emerging Applications of Technology is one example of this approach. It is led by an advisory group comprising "representatives from a range of stakeholders" including national patient interest groups (Oliver et al., 2004).

Finally, lay participants may lead or even control research processes (Turner and Beresford, 2005). The potentially significant impact of lay participant-led research projects has been highlighted particularly in the developing world, where they have occasionally brought to light previously unrecognised public health problems (see Wang, Burris and Ping, 1996, among others). However, lay participant-led research remains largely untested and few evaluations of research outcomes from projects of this form exist. Partly, this is because examples of this approach are rare. There is no evidence of lay participant-controlled strategic decisionmaking in health research, for example. However, an approximate model is provided by a project run by the Centre for Health Policy and Programme Evaluation at the University of Wisconsin's Medical School between 1994 and 1996 (Oliver et al., 2004). Grass-roots organisations were actively engaged from the outset in designing the evaluation tools, before selecting the particular issues they wished to address. Finally, they were trained in appropriate research methods and given ongoing support to conduct their chosen projects.

Although we may draw broad distinctions between degrees of patient and service-user involvement, some important caveats are required. First, patients/service users and researchers may not perceive these levels of involvement in the same way. What may appear to a researcher to be collaboration with consumers may be viewed as little more than consultation or even tokenistic involvement to the patients and service users concerned. Second, the boundaries between different degrees of involvement are not clearly defined; the distinction between consultative and collaborative research is particularly ill-defined, and further research is probably need to clarify our understanding in this area.

CHAPTER 3 What are the drivers for the spread of participatory health research?

Headline points:

- Broad patterns of historical and social change including improvements in level of education and information accessibility, the drive for greater accountability in public services, and changing perceptions of disease and illness have helped created an impetus towards greater participation in health research.
- This has been reinforced by powerful philosophical arguments in favour of participatory approaches, including demands for the democratisation of the research process, the empowerment of individuals, and new efforts to prevent exploitation of research subjects.
- The rise of participation has also coincided with new developments in academia and the policy field, designed to improve the ability of individuals to participate.
- In some cases, particular groups or individuals have acted as powerful campaigners for increased participation.

3.1 The role of complex historical and social factors

3.1.1 Broad patterns of social change

Social change over the past 40 years has played a key part in driving the increase in participatory research. Initially encompassing a greater emphasis on self-mobilisation and individual empowerment, particularly since the 1960s, the broad category of social change also incorporates some of the complex impacts of globalisation; key factors are summarised in Figure 3.1.

Broad patterns of social change have perhaps most importantly been characterised by rising overall education levels in the developed world and elsewhere. Combined with improved access to information – latterly through platforms such as the internet – these developments have helped to bring about fundamental changes in the way in which patients and the public interact with health systems, practitioners and researchers.

In particular, the changes have led to increasing patient demand from the health-care system in general, and from health professionals in particular, partly as a result of the rising power of consumerism since the 1960s (Beresford and Evans, 1999; Beresford, 2000;

Beresford, 2003). A key turning point in the United Kingdom in this context was the publication of the Griffiths Report under the last Conservative government (Department of Health and Social Security, 1988), which argued that, "the NHS needed to recognise and respond to the needs of its customers" (Boote, Telford, and Cooper, 2002). This was accompanied by encouragement of public-service managers to promote a so-called customer-service-oriented culture, and increasing pressure from consumer organisations such as the National Consumer Council (Sitzia and Wood, 1997). As we shall see, consumer pressure has also played an important part in the rise of participatory research in Australia.

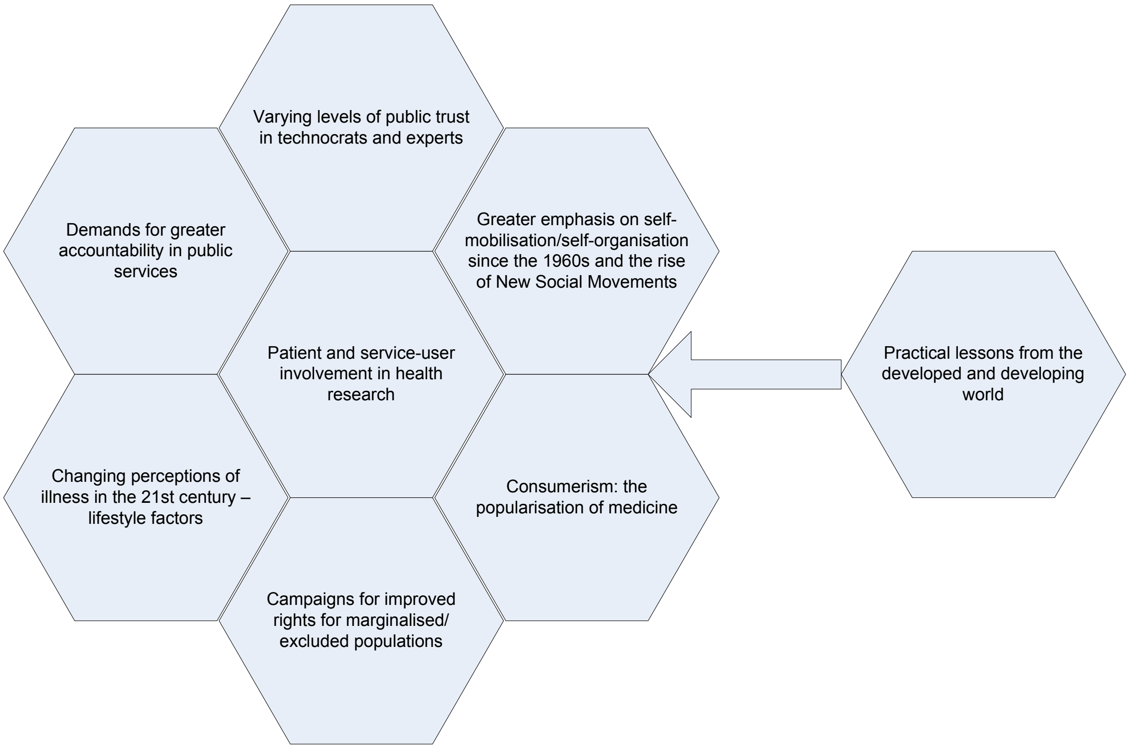

Varying levels of public trust in technocrats and experts
Demands for greater accountability in public services
Greater emphasis on self-mobilisation/self-organisation since the 1960s and the rise of New Social Movements
Patient and service-user involvement in health research
Practical lessons from the developed and developing world
Changing perceptions of illness in the 21st century – lifestyle factors
Consumerism: the popularisation of medicine
Campaigns for improved rights for marginalised/ excluded populations

Figure 3.1—Historical and social factors driving the move towards participatory research in health and other fields

Broader patterns of social change have also been expressed in the increased willingness on the part of patients to challenge so-called experts in medical and scientific research, a manifestation of changing levels of public trust in technocrats and scientists (Collins and Evans, 2002; House of Lords Science and Technology Committee, 2000). Whereas public trust in today's scientists is generally quite high at 64%, there are clear discrepancies according to the area in question: although 88% of the public trust cancer scientists, for example, only 44% have said that they view government scientists in the same way (Barnaby, 2002). Much of this may be related to the effects of a series of scandals on public perceptions (Beresford, 2003). Important early examples include reactions to the physical impairments of newborn children associated with thalidomide in the 1960s, and the UK government's handling of the bovine spongiform encephalopathy/Creutzfeldt-Jakob disease crisis in the mid to late 1990s. More recently, ongoing public disquiet over purported links between the measles–mumps–rubella vaccine and autism in the United Kingdom seems to have manifested itself in opposition to the scientific research establishment, despite overwhelming evidence to the contrary (Milewa et al., in press). Arguably more damaging in terms of public trust in medical research was a series of organ retention scandals at major hospitals in the UK, including Bristol Royal Infirmary and Alder Hey Children's Hospital, both of which led to public enquiries and important changes to the regulatory regime in this area in the early to mid-2000s (House of Commons, 2001).

3.1.2 The demand for greater accountability in public services

At the same time as the willingness of patients to challenge so-called experts in medical and scientific research has increased, public-sector reforms in the developed world since the 1980s have involved an increasing focus, at least in terms of the language used by political proponents, on accountability. In the United Kingdom, greater accountability has been an important underlying theme in the current government's use of publicly stated targets to manage public-sector performance (HM Treasury, 1998). These broader changes have accelerated demands for patient and service-user involvement in research, both to improve the quality of research findings, and to provide a greater level of scrutiny and enforced accountability for researchers than before.

3.1.3 Changing perceptions of disease and illness

The changing perceptions of disease and illness, both within and outside the medical profession, have also played their part. There is evidence that the key health challenges in developed countries stem not from acute or transmissible diseases (i.e. tuberculosis and cholera) but from chronic illnesses (i.e. diabetes and heart disease). Chronic diseases of this kind require a rather more nuanced approach to treatment, however, since the most significant impacts on outcomes are likely to come as much from behavioural changes as the administration of drugs and clinical interventions (Rose, 2008). There is a growing sense that this demands a hitherto unusual degree of cooperation between health professionals and patients/service users in both health-care provision and health research, especially given the increasing importance of patient experience in determining the way in which interventions for chronic conditions are designed.

3.1.4 The growing power of previously disenfranchised groups and minorities

An important feature of this change—in the United Kingdom and elsewhere—has been the role of previously marginalised or disenfranchised groups, who have sought a greater role in defining and running research that involves them as participants. Indeed, the development of participatory methods owes much to the efforts of researchers from various disciplines who work with marginalised or oppressed communities in South America, Asia, and Africa from the 1970s (Minkler, 2004). In Australia and Canada, campaigners advocating greater rights for aboriginal groups have played a key role in driving forward the CBPR and patient/service-user involvement agenda, on ethical grounds and with a view to improving research quality (see the country case studies in chapter 5). Similarly, campaigners for improved rights for the disabled and mentally disabled have had an important driving role in the United Kingdom (Beresford and Evans, 1999).

Internationally, the growth of a well-funded and active AIDS movement has also had a significant impact on the amount of research that has been conducted in this area (Epstein, 1996); combat veterans in the United Kingdom and United States have also been engaged in a similarly high-profile, although less successful, campaign to bring about changes in the research approach to Gulf War syndrome (Zavestoski et al., 2002).

A key outcome of these changes has been the rise of notions of so-called lay expertise, mainly from the field of medical sociology. This concept is gaining increasing currency among participatory and community-based researchers (Prior, 2003). In recent years, the concept of lay expertise seems to have been given official sanction through growing institutional support for participatory research. Internationally, the United Nations Covenant on Civil and Political Rights has provided an important underpinning for moves in this direction (Kuruvilla, 2005). In the United Kingdom, the NHS INVOLVE programme was established in 1996 to help drive increased lay participation in research supported by the health service (see section 5.4).

3.2 Philosophical arguments for participatory health research

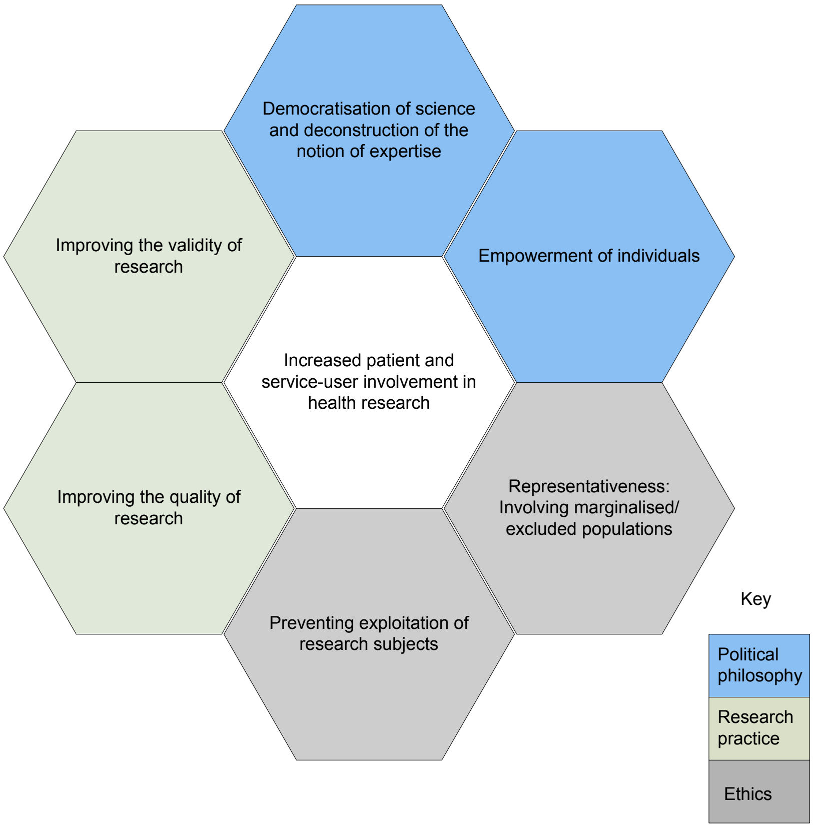

Democratisation of science and deconstruction of the notion of expertise
Improving the validity of research
Empowerment of individuals
Increased patient and service-user involvement in health research
Improving the quality of research
Representativeness: Involving marginalised/ excluded populations
Preventing exploitation of research subjects
Key
Political philosophy
Research practice
Ethics

Figure 3.2—Philosophical drivers towards participatory health research

Beyond the broader historical and social changes that have formed the backdrop to these changes, what philosophical arguments can we identify in favour of increased participation in health research? Broadly speaking, they fall into three categories, as indicated by the colour-coding in Figure 3.2: (1) argument from political philosophy; (2) arguments from ethics; (3) and arguments relating to the research enterprise itself.

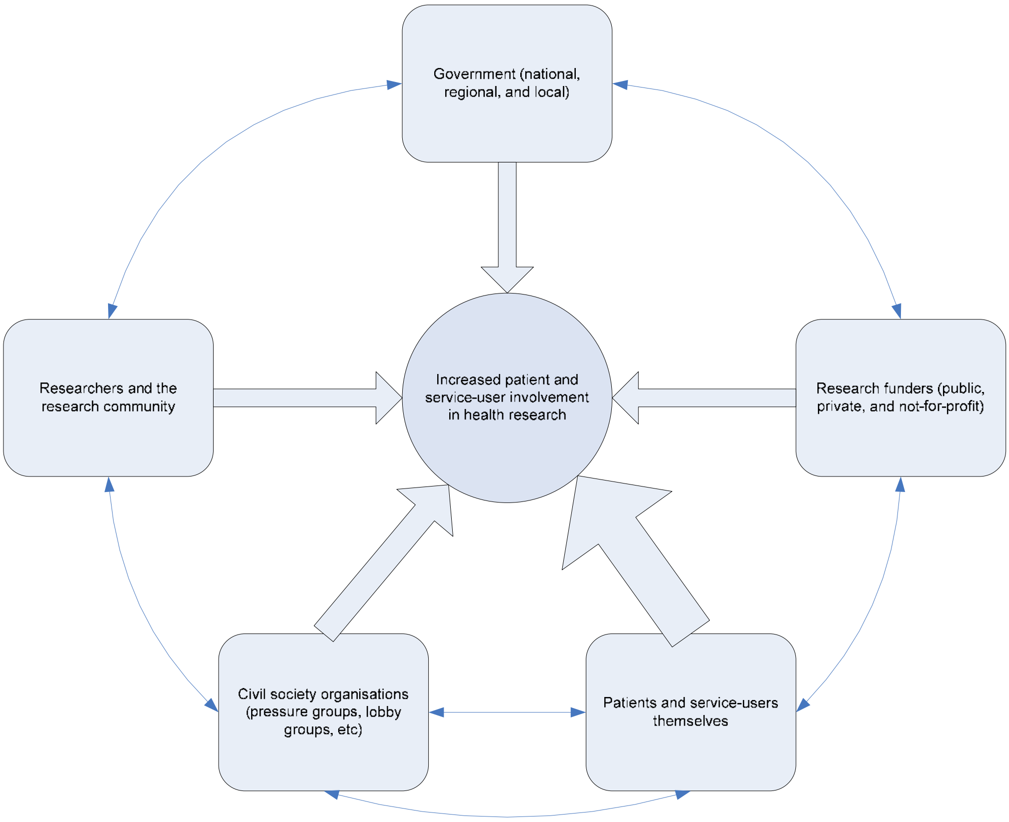
Arguments from political philosophy focus primarily on the so-called democratisation of science, and link closely to the broader historical and social changes outlined above. In general terms, these arguments have focused on promoting the involvement of the public at a strategic level, on the premise that democratic systems of decisionmaking give a central place to participation in open debate, a key theme for advocates of patient/service-user involvement in health research (Viswanathan et al., 2004; Willis and Wilsdon, 2004). This argument has been combined with increasing criticism of the privileged position of researchers in the decisionmaking process. Indeed, the post-modern philosopher Jürgen Habermas has argued forcefully that the notion of an expert culture, whether in medicine or any other field, is essentially anti-democratic (Habermas, 1987).

It is important to note, however, that this view is contested. At a Westminster Fringe Debate in 2005, several leading figures in the scientific establishment—including Professor Colin Blakemore, who was the Chief Executive of the UK Medical Research Council at that time—questioned whether democratisation of science could be seen to be in the public interest in all instances (Stockholm Network, 2005).

Moreover, there are important variations in emphasis within this broader philosophical school depending on the level of involvement concerned. In the United Kingdom, the democratisation argument has tended to be framed as one of citizenship, and stakeholding within the broader political system. There is a sense that because public funding supports a lot of scientific research, taxpayers should have a greater say in strategic decisionmaking in this area (Caron-Flinterman, Broerse, and Bunders, 2007). At the process level, the empowerment of patients and service users is viewed as a mechanism for changing the balance of power between them and vested interests involved in administering and funding the NHS (Boote, Telford, and Cooper, 2002). Some, notably in Australia, have suggested that participation by consumers embodies "notions of individual rights, community responsibility, social justice and accountability" (Bastian, 1998; see also Cornwall, 2002).

There are strong grounds for increased patient and service-user involvement from an ethical perspective too. The perceived responsibilities of researchers to the individuals and communities with which they work are key drivers here. Two important strategic questions should be asked before a research project is embarked on. First, is the proposed research culturally and practically acceptable? Second, how can we ensure that disruption to the community is minimised? New approaches to social work research—particularly with regard to disabled people and consumers who are subject to psychological or psychiatric treatments—have played an important role (Beresford and Evans, 1999; Beresford, 2003).

The avoidance of exploitation is a key theme underlying ethical arguments for participatory research (Resnik, 2003; Emanuel et al., 2004). Building lay participants into the research process helps to ensure adequate information reaches them about the work being conducted and what effects it may have, while providing useful data on patient perceptions of treatments (Resnik, 2001). It may also help to prevent instances in which interventions are introduced without sufficient evaluation, and in particular, without attention to the views of those likely to be subject to them, as has occurred in maternity care in the United Kingdom in the past (Oliver, 1995). The involving of minority and disenfranchised populations (e.g. the aborigines in Australia) has also been seen as important in this context, and is closely linked to the issue of empowerment (Tindana et al., 2007).


Government (national, regional, and local)
Researchers and the research community
Increased patient and service-user involvement in health research
Research funders (public, private, and not-for-profit)
Civil society organisations (pressure groups, lobby groups, etc)
Patients and service-users themselves

Arrow size indicates the relative strength of the influence from each of the constituent groups.

Figure 3.3—The contributions of various societal actors to driving participatory health research

Perspectives on the rights of patients (and participants in research more generally) cut across the boundary between political and moral philosophical arguments. This strand of thinking concerns both strategic- and process-level involvement, and is most clearly articulated in a series of articles published in the *BMJ* in 1995 (Chalmers, 1995; Goodare and Smith, 1995; Oliver, 1995), although there are also strong precedents for it outside health research (Cornwall, 2002). Proponents of patients' rights argue that patients should come first in the design of health research programmes, since "the whole purpose of conducting trials is to benefit patients" (Goodare and Smith, 1995). They should be directly involved in helping to set the research agenda, whether by defining the outcomes to be studied, designing the research programme, or setting the level of consent required for individuals to participate.

An important impetus for this kind of work comes increasingly from those working in the field of health research itself—our third category—and relates to the nature of the research enterprise. A primary motivator for this has been the growth in the body of evidence showing that health status is determined by a complex set of contextual factors—social, economic, and physical environmental—after a decade in which randomised controlled trials[6] and individual risk-factor models (based on genetic susceptibility) were arguably dominant (Rose, 2008). It is now widely recognised that communities bring particular experiences and skills to bear on our understanding of these issues (Israel et al., 2001). On the one hand, patients and service users bring perspectives to scientific research that investigators themselves would not be able to, especially the experiential dimension. On the other hand, they may highlight new areas for research agendas that do not normally receive much attention from the scientific community through daily contact with the issues (Caron-Flinterman, Broerse, and Bunders, 2005). This has coincided to a large extent with the emergence of the quality agenda in health service provision. Firstly, there is a sense that participation will greatly help to improve information sharing about experiences with a view to driving up the quality of health service provision (Brook, 2008). Secondly, the move towards co-production of health interventions in certain areas (e.g. diabetes, obesity, and kidney disease) has been based on an emerging consensus that patient and service-user involvement can make a real difference to treatment outcomes if it is handled appropriately (Hibbard, 2003).

The arguments advanced above take as their premise the sense that increasing participation in health research is a positive development. While few would challenge this basic assumption, there is growing concern that in its current forms, participatory research may be little more than an advanced way of co-opting and controlling participants. Critics charge that it achieves this either by legitimising decisions that have already, in fact, been made, or reducing dissent by offering the appearance of participation when in reality lay participants have little or no *real* influence on the conduct of research (Cooke and Kothari, 2001; Cornwall, 2000; Khan, 1999).

From a philosophical perspective, some authors have also suggested that self interest on the part of participants may inevitably skew the results of participatory research projects. They contend that some people may act primarily to satisfy self interest even where there is clear evidence that collective action leads to both public and individual benefit (Hardin, 1968).

3.3 Immediate academic and policy drivers for participatory research

These broader historical, social and philosophical developments have coincided to provide support for emerging trends in academia and the public policy work towards greater participation. In academia, growing interest in the potential of Action Research, Participatory Action Research (PAR), programme evaluation and knowledge utilisation research (see box below for definitions) have helped to break down historical barriers between research and practice. From a policy perspective, growing interest in the potential of applied research to impact on policymaking has seen a dramatic increase in the number of centres specialising in this kind of approach on both sides of the Atlantic since the 1970s (Denis and Lomas, 2003).

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[6] The randomised controlled trial is a method most often used to test the efficacy of health service interventions, or particular health technologies, although it is increasingly being used in social research and other fields. It is based on the random allocation of various interventions to research participants, thereby ensuring that known and unknown confounding factors are controlled for in any results obtained.

Action Research is based on the assumption that knowledge about social or organisational systems is gained by trying to implement change within them. It sees collaboration as a necessary part of knowledge accumulation, since knowledge acquired by scientists operating in isolation in a laboratory context is not “real”.

Participatory Action Research is premised on the basis that collaboration is a political necessity. It relates closely to broader arguments about the democratisation of knowledge and the empowerment of groups often marginalised from research processes.

Programme evaluation is a growing field in applied research. Participation is viewed as a pragmatic requirement, with a view to maximising the impact of research findings on policy and practice.

Knowledge utilisation research examines the application of research in practice, and – as for programme evaluation – takes participation as a pragmatic requirement for success.

Box 3.1—Common forms of participatory research.

3.4 Patients, service users, and other actors as drivers of participation

Whereas several groups have played their part in driving the participatory health research agenda (see Figure 3.3), in the immediate term, societal actors have proven the most potent driving forces for increased participation in health research in many countries, at both strategic and process levels. In some instances, the impetus has come from patients and service users themselves, acting in groups to advocate the rights of marginalised or disenfranchised groups. Activism of this kind has been an important driver of change with regard to patient safety, but its impact on health research is rather more doubtful.

CSOs and, on a larger scale, social movements have been key drivers for this change, although mostly at a strategic level. In some instances, this has involved wholesale changes to the research agenda, as was achieved by AIDS activists in the 1980s when little was known about the disease, and the scientific research establishment showed remarkably little interest in directing its energies towards it (Epstein, 1995; Epstein, 1996). A similar effect has been achieved, although with markedly less publicity, by Gulf War veterans with respect to the putative Gulf War syndrome (Brown et al., 2004).

In some countries, government has played a prominent part in driving forward the patient and service-user involvement agenda. This is particularly the case in the United Kingdom. As suggested earlier, the Griffiths Report set down important recommendations in terms of accountability in government and public affairs that gradually penetrated the scientific research field and encouraged increased strategic level participation in decisionmaking (Boote, Telford and Cooper, 2002). More recently, the rhetoric of citizen empowerment and so-called personalisation of public services has spurred a range of government-funded initiatives to promote patient and service-user involvement at process level, including the NHS's INVOLVE programme, established in 1996.

Researchers and research funders also increasingly advocate patient and service-user involvement, although their motivations for doing so may be quite different. Since the bulk of UK health research is government funded, for example, the impetus for increased involvement in the activities of public research bodies has been strongly linked to the drive in this direction from central government. However, for third-sector research funders, it is usually a question of responding to demand from donors to their activities. In the United Kingdom, the Health Foundation strongly advocates lay involvement in all its research projects, not least because they are primarily focused on improving the quality of patient care available.[7] For researchers, the adopting of a participatory approach may reflect either a genuine acknowledgment of the potential improvements in research quality that may be brought about by patient and service-user involvement, or resignation to the reality of their diminished status in power relations between scientists and the citizen, and a pragmatic response to the requirements of their funders in this new reality.

Case study— the NHS INVOLVE programme

The NHS INVOLVE programme was established in 1996 to "promote public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used".[8] Its core aims are to:

1. Develop "key alliances and partnerships" for the promotion of public involvement in health research
2. Develop an environment in which members of the public can become involved constructively in research, and
3. To disseminate knowledge on public involvement in health research (NIHR, 2007).

It is funded by the UK Department of Health, and currently administered by the National Institute of Health Research, and provides and advisory and support function for health researchers in the UK looking to take a more inclusive approach to their work.

The INVOLVE programme has both an advisory and a consultative function. On one hand, it has produced publications on everything from training for service users and researchers (Lockey et al., 2004), to guidance on how to build effective user-controlled projects (Turner and Beresford, 2005). On the other, it also includes a panel of around 20 individuals that meets four times a year, bringing researchers together with a combination of service users, informal carers, representatives of voluntary organisations, and health and social service managers. It publicly advertises for new members for its working groups every two to three years.

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[7] The Health Foundation's Web site (http://www.health.org.uk/) carries details of many of these projects. An interesting current example is the Quest for Quality and Improved Performance, a five-year programme that is gathering data from a wide range of sources, including patients, to inform its efforts to better the quality of care provided in the United Kingdom.

[8] INVOLVE website: http://www.invo.org.uk/About_Us.asp (as of September 29, 2008).

CHAPTER 4

Does participatory health research work?

Headline points:

- Evaluating participatory research approaches is difficult because variations between them are so great that cross-comparison is hard; supporting evidence is also thin.
- A "5 E" approach may provide a useful framework for evaluation, in recognising the importance of impact on efficiency, effectiveness, equity, ethics and empowerment.
- Improvements in efficiency cannot generally be considered a primary motivation for adopting a participatory approach since costs – both financial and in time spent – usually rise when lay people are involved.
- Lay participation may improve research quality, but the evidence is not conclusive.
- Participatory research often improves representation of otherwise marginalised groups, but it can never be *truly* representative.

One of the key challenges when assessing whether research works is to identify appropriate criteria for making informed judgments. In the case of participatory research, this is particularly difficult. Should we look for measures that merely assess the extent to which the scientific research process has been democratised, in line with some of the key philosophical arguments in favour of the participatory approach? Or should we seek more comprehensive measures that perhaps enable cross-comparison with other approaches to scientific research? And how far do current approaches to participatory research really fulfil the philosophical arguments (e.g. concerning equity and empowerment) frequently made in their favour? In this section we try to address some of these issues by putting forward a framework for evaluating participatory health research. We use this to identify some of the key strengths and weaknesses of this approach to health research.

4.1 Constructing a framework for evaluating participatory research

Strong arguments have been made elsewhere to suggest that, unless the values and assumptions underlying health research impact measures are discussed and defined by a broad range of stakeholders, their validity and even relevance may be questionable (see Coast 2004 for a discussion of this issue with regard to economic evaluation of health interventions). In the last chapter, we outlined some of the most important drivers underpinning the emergence of participatory approaches to health research over the past 30-40 years, and found that philosophical arguments relating to ethics, equity and empowerment have been just as important as the need to improve research quality and efficiency. Any evaluation framework used to assess whether or not participatory approaches as currently practiced, "work", must engage with these concerns.

In this report, we adopt a framework for evaluating participatory research based around five "E"s: Efficiency, Effectiveness, Equity, Ethics and Empowerment. We do not view participation as an end in itself. The elements of the framework we have developed are outlined in Box 4.1, along with some examples of the kinds of considerations that might be included. It should be noted, however, that the precise dimensions of evaluation will often depend on the nature of the research project in question.

Dimensions of Efficiency

- Monetary cost of research
- Time taken to complete research projects
- Recruitment and retention of participants for research projects

Dimensions of Effectiveness

- Reliable impact on the quality of the research process
  (e.g. formulation of the research question, validity of the research process)
- Reliable impact on the quality of research outcomes

Dimensions of Equity

- Representation of "socially excluded" groups and sub-groups
- Form and extent of representation in the research process
- Distribution of access to resources in support of the research

Ethical considerations

- Accountability of scientific researchers, and of the research process as a whole
- Processes of consent for participants in research and prevention of exploitation
- Realisation of the "rights" of research participants
- Health and safety considerations

Empowerment

- "Ownership" by participants in the research
- Capacity-building among research participants

Box 4.1—A theoretical basis for understanding whether participatory research works, focusing on the research process, rather than strategic-level considerations

In the discussion that follows, we focus mainly on process-level involvement, rather than strategic-level participation, an approach dictated in large measure by the poverty of the evidence base on what works in this area. Much of what we know about the impact of participatory research is derived from anecdotal examples or case studies assembled by researchers and research organisations. Very few comprehensive evaluations exist, and certainly none attempt to draw comparisons between participatory and non-participatory approaches. Although some interest is emerging in frameworks for evaluating public participation exercises in general, little of this work has been specifically applied in the field of health research thus far (Rowe and Frewer, 2000; Rowe and Frewer, 2004).

4.2 Towards an assessment of participatory health research approaches

It is difficult to comprehensively assess the strengths and weaknesses of participatory research approaches. First, though the presumed benefits of participatory health research are well rehearsed, conclusive evidence for them is elusive. Many of the arguments advanced in favour of this kind of research are essentially pragmatic because it is seen as advantageous in the face of consumer demand or even non-cooperation with health researchers (Oliver et al., 2004). Second, variations in approaches to participation mean that it is difficult to draw general conclusions about the extent to which goals around equity, ethics and empowerment are realised. By and large, these assessments must be made on a case-by-case basis. In this section, therefore, we provide general observations rather than a detailed evaluation of participatory approaches.

4.2.1 Efficiency

Participatory approaches may improve future recruitment and retention for projects

There is some evidence that participatory approaches increase efficiency by improving the recruitment and retention of participants for research projects (see for example, Marais, 2007). This is not conclusive, however, and further work is needed.

But the financial and time costs of participatory research may be high

From an efficiency perspective, it is often argued that, although increased participation may be desirable, the costs (financial and time) of integrating lay participants into both the research process and strategic decisionmaking may outweigh the advantages it brings. Engaging with lay participants during research requires the devotion of more resources to meetings and communicating early results, covering travel and subsistence costs, and possibly childcare and carers' expenses (UK Department of Health, 1999). However, the argument of increased cost may simply reflect the fact that existing financial structures and procedures for supporting research in many scientific establishments do not take the prospect of lay involvement into account (Caron-Flinterman, Broerse, and Bunders, 2007).

A more damaging claim is that participatory strategic decisionmaking is more susceptible to conflicts between researchers and community members, whether over funding, different research emphases, or understandings of the research question (Israel et al., 1998). An important issue is the distribution of funding between different aspects of research; the balance of emphasis on process issues and research outcomes is often cited, with lay participants apparently more focused on the outcome than are researchers (Buchanan, 1996; Plough and Olafson, 1994). However, as elsewhere, it is difficult to be certain of the prevalence or impact of conflicts of this kind, because most of the evidence available is anecdotal.

4.2.2 Effectiveness

Lay participation may help to improve research quality

At a fundamental level, lay participation helps to improve the quality of research conducted, possibly because of a better understanding of the research question or improved execution. Some argue that having the broader or different perspective on research questions provided by lay participants is in itself an advantage (Griffiths et al., 2004). Anecdotal evidence suggests that consumers may bring perspectives on the likely impact of health interventions, or even varying understandings of illness and its effects, that would otherwise be inaccessible to health researchers, especially given the tendency among medical researchers to pathologise illnesses, and issues that may be affected by much wider sets of determinants (Entwistle et al., 1998; Griffiths et al., 2004; Caron-Flinterman, Broerse, and Bunders, 2007). Lay participation may help to direct research so that it is more relevant to practical concerns by identifying issues that are of real concern to patients and service users (Griffiths et al., 2004). Finally, participatory approaches may also help to improve the quality of interventions that are developed from research findings. Some have suggested, for example, that mental health and social work interventions that are based on participatory research are more responsive to the needs of patients and service users because their views have been built into the design from an early stage (Griffiths et al., 2004), and that health outcomes have improved as a result. Nevertheless, the impact of participatory methods on research quality is unclear; a recent study used a research outcome scoring system to confirm that, whereas there was no suggestion that participatory approaches reduced research quality, evidence that it improved it was not forthcoming (Viswanathan et al., 2004).

Unfortunately, the claim of improved quality is ill defined, and it is unclear whether such research is better because it is methodologically or ethically superior, or because it is more likely to influence policy and practice (Oliver et al., 2004). Moreover, beyond a number of frequently cited anecdotal examples of the impact of patient and service-user involvement on research programmes, systematic supporting evidence for some of the claims made has proved elusive. One important recent study of the advantages of consumer participation in mental health research is based on a stakeholder survey, rather than on systematic evaluations of participatory research programmes (Griffiths et al., 2004). In truth, it is very difficult to say with any certainty whether or not these improvements can be attributed to the use of participatory methods per se (Viswanathan et al., 2004).

And may improve relations between researchers and service users

Proponents of lay participation in health research have also highlighted the potential for improvements in relations between patients/service users and the research community. In part, this stems from the improved accountability of researchers to citizens that participatory research offers (Griffiths et al., 2004). But by involving lay participants in research from the outset, this approach also helps to build understanding of research issues, of the process more generally, and of technical issues that might otherwise be inaccessible to citizens. Such involvement may also contribute to improved uptake of research results, not least because participatory approaches help to secure buy-in from community members who might otherwise be resistant to the interventions in question (Caron-Flinterman, Broerse, and Bunders, 2007). Some suggest that research findings are more likely to be successfully implemented when they are part of campaigns that involve groups of mobilised citizens (Sanders et al., 2004).[9]

Uptake of research results is also sometimes improved

Finally, it has been suggested that the results of participatory research are more successfully taken up by comparison with alternative approaches, because of the applied subject-focus of many participatory research projects (Goodare and Lockwood, 1999). Evidence for this is – thus far – largely anecdotal, however.

But researchers often counter that the requirement for participation compromises quality

It is widely held within the research community that lay participation decreases the quality of research conducted. Arguments for this viewpoint are straightforward: lay participants simply do not understand the complexities of the research process or the theories underlying the issues, and therefore cannot contribute meaningfully. Others suggest that consumers must be imbued with certain characteristics for research to be effective: these include being “well organised, skilled in advocacy, thoughtful in their approach and accountable to, and representative of, a range of people” (Goodare and Lockwood, 1999). There is, however, little clear evidence to support this view, and negative effects may be offset by improving the quality of training provided for both researchers and lay participants to facilitate group-working (Boote, Telford, and Cooper, 2002). Training availability is improving in a number of countries; in the United States it is now provided by Project LEAD,[10] and in the United Kingdom by the College of Health, the Critical Appraisal Skills Programme,[11] and the Royal College of Psychiatrists, the last of which are currently pioneering a programme that trains researchers and lay people together.

And new biases may be introduced

A related charge is that lay participation introduces new biases into the research process that may reduce quality by skewing research findings. This applies principally to strategic decisionmaking. For example, heavy lobbying by single-issue CSOs may result in projects being directed to more closely address their concerns, but there is no guarantee that they adequately reflect the complexities of a research topic. However, clear evidence for this charge is not forthcoming. Objections seem to be based largely on the observation that the public may exhibit different research priorities from the research community at large

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[9] Mobilisation of citizens in this way is not always a positive force; consider the case study on trials of tenofovir in several developing countries (see section 5.6).

[10] Information on Project LEAD can be found on the National Breast Cancer Coalition Web site: http://www.stopbreastcancer.org/index.php?option=com_content&task=view&id=395&Itemid=138 (as of September 1, 2008).

[11] The Public Health Resource Unit Web site provides information on the Critical Appraisal Skills Programme: http://www.phru.nhs.uk/Pages/PHD/CASP.htm (as of September 1, 2008).

(particularly with respect to health services), and it is difficult to find examples of instances where public lobbying has damagingly skewed research focus in this way (Bowling, 1996).

Interestingly, it has also been suggested that, by increasing the range of stakeholder influences over the research process, the final impact of research projects may be reduced. The charge here is that ownership over research results becomes compromised, with the result that translation does not occur as effectively (MacFadyen and Farrington, 1997). Although further evidence is required to understand the nature of the claim, evidence suggests that highly motivated investigators do play an important part in driving their research findings towards translation, suggesting that complicated ownership arrangements may indeed affect the wider impact of scientific research (Wooding et al., 2004).

4.2.3 Equity

Participatory research often improves representation of "socially excluded" groups

It is widely recognised that, historically, health research has rarely addressed the concerns of socio-economically deprived communities and minority populations that often carry a disproportionate burden of morbidity and mortality (Israel *et al.*, 1998). This is partly because these populations are often under-represented in research projects. A desire to overcome this deficit has been a key motivation for the development and spread of new methods for participatory research. The growing prevalence of participatory projects among, for example, aboriginal and socio-economically deprived populations in North America (see Chapter 5 for more details) attests to the growing success of these efforts. RAND Health has taken a leading role in establishing several such programmes, including Witness for Wellness, addressing depression in minority communities in Los Angeles, and work with community partners in New Orleans to develop culturally-appropriate mental health services in the city (RAND Health, 2008).

But it can never be truly representative

On the other hand, critics argue that the selection of lay participants in health research can never be truly representative. First, some authors question whether the idea of a consumer representative is itself valid, since different individuals will invariably have different—sometimes even conflicting—views on health research issues (Hanley et al., 2001). Second, there is a natural tendency to favour the sick over the well when choosing participants for health research, not least because their need is often most urgent. But health research must engage with those not directly affected, especially if we are to gain a better understanding of wider, social determinants of health (Boote, Telford, and Cooper, 2002). Third, there are concerns that many of those who get involved in research as lay participants are self-selecting; current approaches to participatory research often favour individuals who can advance their case for inclusion more clearly than others (e.g. patient activists) (Entwistle et al., 1998). Finally, there are concerns that as patients and service users become more involved, they too become professionalised, viewing the research process increasingly from the perspective of the researchers and failing to communicate the lay perspective (Boote, Telford, and Cooper, 2002).

Most of these objections ultimately support the conclusion that participatory research inherently comprises trade-offs in the context of representation, and pose the question of whether true representativeness is really required. The answer to this question ultimately depends on the kinds of knowledge that are sought from particular research projects. One researcher, for example, has suggested that "it might be helpful to think about seeking consumer perspectives rather than consumer representatives" (Boote, Telford, and Cooper, 2002). Others have insisted that the focus should be on inclusion and diversity of service users, rather than representativeness, to ensure that inequalities are not generated (Beresford, 2007).

4.2.4 Ethics

The extent to which ethical considerations – such as the need for consent, and due attention to health and safety concerns – are recognised in individual research programmes can only be assessed on a case-by-case basis. Nevertheless, there have been important moves to develop ethical guidelines for participatory research especially in those countries where much of the effort has been focused on involving aboriginal populations. By and large, these focus on encouraging dialogue between researchers and lay participants over a range of issues, including (Macauley *et al.*, 1999):

- Research goals and objectives
- Methods and duration of the project
- Degree and types of confidentiality
- Current and future use of data and biological material, where this is filed as part of the research process.

More recently, there have been efforts to define more closely standards of ownership, control, access and possession (OCAP) for individuals and groups as part of a wider campaign for greater self-determination for Aboriginal populations (Schnarch, 2004). It remains to be seen how far these will be adopted.

4.2.5 Empowerment

A number of studies highlight the positive impact of participation on empowerment

Somewhat surprisingly, very few studies have highlighted the impact of participatory research projects on increasing the capacities of lay participants (as opposed to the capacity of researchers to conduct valid and high-quality research). An important exception is a recent review of 60 U.S. studies conducted by the Agency for Health Research Quality, which found that 47 reported improved community capacity arising from participatory projects, defined in several ways: (1) an enhanced capacity to create change as a result of the research findings, (2) improved chances of obtaining follow-on funding, (3) skills building, and (4) partnership and coalition development (Viswanathan et al., 2004). These benefits came in addition to readily identifiable improvements in the research skills of lay participants.

4.3 Realising "Five E" participation: some key barriers and facilitators

We have suggested that participatory health research should aim to be efficient, effective, equitable, ethical and empowering. Besides the more general benefits and disadvantages of lay participation in research identified above, several key barriers to this kind of "five E" involvement have been identified. Many are closely linked to issues raised in sections 4.1 and 4.2, and apply equally to both strategic- and process-level involvement. Box 4.4 outlines some of the key areas concerned. Again, however, the evidence base here is mainly suggestive, being based primarily on anecdotal accounts.

4.3.1 Familiarity with research topics

Familiarity with research topics or areas can be a key barrier: specifically, are participatory approaches to research more appropriate in some fields than in others? This remains an open question, the debate being spurred partly by the observation that, although increasingly common in fields such as mental and public health research, participatory methods are rarely discussed in the biomedical research field (i.e. nearer the basic end of the research spectrum). Some authors see the tendency of health researchers to pathologise illness and disease in the biomedical field as a key barrier to community-based work, the assumption being that lay participants will not have the expertise to contribute in a meaningful way. Others see a natural avenue for participatory approaches that emphasise underlying health determinants and strategies of social change, alongside this pathologising tendency (Sanders et al., 2004). They argue that participatory approaches are no less applicable to biomedical research than to other areas, even if the supposedly technical character of the field might seem to make it less accessible (Caron-Flinterman, Broerse, and Bunders, 2005). Indeed, there are areas in which community-based approaches are increasingly recommended—notably research on health disparities (Wells et al., 2006).

- Familiarity with the research field in question
- Working relationships
- Attitudes of research partners
- Programme resources
- Communication
- Leadership
- Training and support

Box 4.4—Summary of key determinants of success for participatory research projects

4.3.2 Working relationships

In a context in which familiarity with the key research topics and issues is in question, working relationships can become difficult to manage. This is exacerbated by the fact that most lay participants are required to adapt very quickly to alien working environments, and have difficulty building strong personal relationships with researchers and policymakers in this environment, especially if they feel isolated and outnumbered. It is quite common, for example, for research committees to contain only one or two lay members (Oliver et al., 2004). Continuity is widely seen as important in helping to build effective working relationships for research (Lindenmeyer et al., 2007).

4.3.3 Attitudes

Attitudes are widely perceived as a key barrier to effective participation. Power relations are thought to lie at the heart of this problem. Some contend that persistent lack of trust between researchers and lay participants will ultimately undo moves towards greater participation: researchers do not always see the value of including consumers in their research, whereas some consumers may push for a user-led approach to projects when this is not appropriate (Israel et al., 1998). However, critics argue that the historically inequitable distribution of power between researchers and lay participants in research (i.e. weighted overwhelmingly towards the former) can never be completely overcome, and community members are right to be sceptical of the language of equal partnership (Israel et al., 1998).

Others argue that the architecture of the research world is inherently unsuited to participatory research (e.g. Caron-Flinterman, Broerse, and Bunders, 2007). They argue that reductionism and the increasing level of specialisation in many fields of health research means that the starting points of researchers and lay participants is often so distant that it may be impossible to reconcile them, even with training and support.

It is occasionally claimed that lack of detailed knowledge of scientific issues by lay participants means that they often do not have the levels of objectivity required to contribute meaningfully to research projects (Caron-Flinterman, Broerse, and Bunders, 2007). In a committee environment, these attitudes can have quite damaging results, either because researchers fail to build lay participants into the process, or because lay participants seek to delegate decisionmaking authority to individuals that they perceive to be experts (Oliver et al., 2004). Finally, cynicism on the part of lay participants can in itself be damaging, not least the charge of tokenism.

4.3.4 Programme resources

We have seen that time constraints can be a key point of perceived inefficiency for participatory health research. In general, lack of time a major barrier to increasing the extent of participation in research. This is particular problem because of the contention of some authors that focus groups and workshops are often considered too limited and short to offer constructive feedback from lay participants on the range of issues that may be involved in a research project (Oliver et al., 2004). However, anecdotal reports suggest that where sufficient resources have been devoted to participatory research programmes, the relationship with lay people is perceived to have worked better, with some programmes offering payment to incentivise involvement (Oliver et al., 2004).

4.3.5 Communication

Communication is a crucial determinant of the effectiveness of participatory research, especially if the topic or issue in question may be unfamiliar to lay participants. Oliver and colleagues (2004) found some evidence that advance information provided to participants was either insufficient or too general in a number of cases. However, the language of communication presents a challenge for researchers, especially in more technical fields around biomedical research (Caron-Flinterman, Broerse, and Bunders, 2007). In any event, good communication is a significant advantage for lay involvement (Oliver et al., 2004).

4.3.6 Leadership

At least one study has found that commitment to lay participation on the part of committee chairs is an important facilitator for participatory research. In situations in which lay members have themselves taken charge of research committees, the study found that, "this was viewed positively by professional colleagues and consumers" (Oliver et al., 2004).

4.3.7 Training and support

Deficits in the provision of training in preparation for patient and service-user participation in research have frequently been cited as an impediment to successful practice (Lockey et al., 2004). It is not simply that training is often not available; what training is provided is diverse in style and content, and usually geared towards one particular group. Moreover, language is often cited as a problem. Effective training needs to help demystify research, providing the basis for joint working between researchers and lay participants (Lockey et al., 2004).

Research funding bodies show increasing awareness of the importance of adequate training. The Cancer Council of New South Wales in Australia, for example, currently runs a three-pronged programme based on oral information, interaction with researchers, and written resources to help train consumers to review research proposals (Saunders et al., 2008). Although the impact of this programme is untested, it provides an interesting model for other research bodies elsewhere.

CHAPTER 5 Lessons from international experiences

Headline points:

- Important differences of approach have evolved in countries in which participatory health research is best established, partly as a result of differing institutional histories and political dynamics.
- The UK has developed a large programme supporting participatory research, led primarily by the National Health Service through the NHS INVOLVE initiative.
- In Australia and Canada, much of the impetus for increased participation in research has stemmed from acknowledgement that the rights of previously marginalised populations – particularly aboriginal populations – needs to be better recognised.
- There may be important lessons for the conduct of participatory research in developed nations from previous experiences in the developing world.

In this chapter, we review some country-level experiences of participatory health research, with broad findings summarised in Table 5.1. In some countries (i.e. the United Kingdom), there is a lengthy history of participatory research in a range of health and health-related fields as well as strong institutional support for these initiatives, whereas in others (i.e. the United States) the extent of these initiatives is more patchy. To some extent this reflects varying institutional architectures: a history of much greater centralisation of health governance in the United Kingdom than in the United States, for example. In other cases, it reflects recognition of ongoing difficulties in relations between researchers and politically marginalised or disenfranchised populations: aboriginals and Torres Strait Islanders in Australia, for example. The Netherlands stands out as an unusual example: a longer history of close relations between leading universities and their surrounding communities has resulted in a broader range of grass-roots approaches to consumer involvement in research, and a model that is now being transferred to other locations in Europe with European Union support.

5.1 Minority rights and participatory research in Australia

Concern for disenfranchised or marginalised communities has been a strong driver for increased focus on patient and service-user involvement in health research in Australia, going as far back as the mid-1980s. A national workshop on the ethics of research in aboriginal health was held in Australia in 1986, sponsored by various community-focused health non-governmental organisations. Since then, the National Health and Medical Research Council (NHMRC), the county’s largest public funder of health research, has highlighted the importance of participatory involvement at the process level in guidelines on research involving aboriginal and Torres Strait Island populations (NHMRC, 1991), and this call has been reiterated in a number of strategic documents in the intervening period, including its national research strategies for 2000–2003 and 2003–2006 (NHMRC, 2000; NHMRC, 2003a). More recently, the NHMRC has published a guidance framework for researchers on how best to involve patients and service users from disenfranchised communities in their work (NHMRC, 2003b).

Table 5.1
Summary of the key features of international experiences with participatory research

Country	Level of involvement	Who is doing it?	Who are the agents?	What are the drivers?
Australia	Mainly process	NHMRC Australian Consumers’ Health Forum Some reseach-funding charities	Government CSOs (e.g. Australian Consumers’ Health Forum) Research funders	Ethical arguments Consumer advocacy
Canada	Mainly process	Canadian Institutes of Health Research Some research-funding charities (e.g. Canadian Arthritis Network)	Government CSOs	Ethical arguments Government policy
Netherlands	Mainly strategic	ZonMw Science shops attached to universities	Government CSOs	Social historical factors Government policy
United Kingdom	Both strategic and process	NHS INVOLVE Learned societies (e.g. Royal College of Psychiatrists)	Government Patients/service users CSOs Funders	Government policy Social historical factors
United States	Both strategic and process	NIH Some research-funding charities including Veterans’ Associations	Patients/service users CSOs Funders (to a limited extent)	Consumer advocacy Social historical factors

Work on building participatory approaches to research with aboriginal populations by public funding bodies was paralleled, from the early 1990s, by an emerging drive in this direction from civil society. The Australian Consumers’ Health Forum has played an active role in driving increased consumer involvement across the board, making a number of supporting statements since the 1990s and supporting projects particularly in the field of ageing research. Since the early 2000s, the campaign group has worked alongside the

NHMRC to produce statements advocating participatory approaches to research and encouraging greater strategic-level involvement for lay people, based on consultations with consumers and communities (NHMRC, and Consumers' Health Forum of Australia, 2001). It has also produced a model framework for consumer involvement in association with the NHMRC (NHMRC, and Consumers' Health Forum of Australia, 2005).

Finally, there is increasing evidence of interest in participatory methods from smaller, non-profit research funders. One example is the Australian Foundation for Mental Health Research (AFFIRM), which supports "innovative, community-based mental health research providing non-clinical, accessible support and effective 'first aid' options for common mental health disorders".[12] However, it is unclear how far participatory methods have become more widely embedded in the practice of health researchers in Australia in the absence of reliable data on the prevalence of community-based research practices. There is also little evidence on strategic-level involvement in research governance in Australia.

5.2 The participatory research environment in Canada

As in Australia, concern for the rights of disenfranchised or marginalised aboriginal populations has been an important driver towards increased patient and service-user engagement in health research in Canada. However, this argument has been taken a step further by the Canadian Institutes for Health Research (CIHR). A recent document on community participation recognises not just the validity of engaging consumers in health research as a means of democratising the research process, but also acknowledges that communities and individuals may even suffer harm if processes are inadequately designed (CIHR, 2007).

Apart from the ethical argument, there is also some indication that Canadian researchers view participatory research as an important tool in exploring some of the most intractable health inequalities and the wider social and environmental determinants to which they may be related (Flicker et al., 2008). This is supported by a recent review of community-based research practices in Canada, which found that many of these studies focus on historically marginalised or under-recognised communities: 23% on aboriginal/first-nation health issues, and 15% on those relating to the lesbian and gay community. Poverty (29%), education (29%), and housing (22%) were the most popular issues of study in a recently conducted survey of community-based researchers in Canada (Flicker et al., 2008).

As elsewhere, community-based research is a relatively new area of activity, and practice is not strongly embedded, with the majority of researchers having three years of experience or less with relevant methods. Interestingly, most community-based researchers are academics or hospital based, which suggests a certain level of support from within the health research establishment. With respect to types of practice, attitudes vary, but the CIHR's guidance recommends a participatory approach in which community members are actively involved at every stage of the research process: from question formulation to execution and delivery of findings (CIHR, 2007).

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[12] See AFFIRM's Web site: http://www.affirm.org.au/research.htm (as of August 31, 2008).

By contrast with the situation in Australia, there is little evidence to suggest that CSOs have played a significant part in actively supporting participatory approaches to health research in Canada, and indeed, evidence of strategic involvement in research governance is in short supply. Consumer advocacy groups that openly advocate participatory health research methods are difficult to identify, and although there is evidence of some CSOs providing support for this kind of approach (e.g. the Women's Health Research Network[13]), this activity seems to be fairly limited at this stage. This may reflect the breadth of state health-care provision in Canada, and the fact that national-level policy, as exemplified by the CIHR, clearly supports participatory research.

5.3 Science shops and social movements in the Netherlands

Participatory approaches to research have a rich history in the Netherlands, reflecting close engagement between many of the country's leading universities and the communities in which they are embedded. They are embodied in so-called science shops, vehicles for collaboration between researchers and the wider community over the definition and selection of research questions that evolved from the early 1970s onwards, particularly from the environmental movement (Leydesdorff and Ward, 2005). Unusually, the science shops have historically engaged lay participants primarily in strategic decisionmaking.

As a response to the perceived isolation of the scientific research establishment in the Netherlands and its overwhelmingly elite focus, independent science shops emerged in several Dutch universities in the 1970s and early 1980s, with the aim of promoting research ideas from within the community (Farkas, 1999). They were also intended to provide scientific research to the emerging left-wing social movements of the 1960s and 1970s, which had little capacity at the time to generate work of this kind themselves (Farkas, 1999). They subsequently evolved into more-or-less formalised establishments through which universities solicited research ideas from interest groups (often environmental organisations, neighbourhood associations, and nursing homes) and individuals, before matching university students to answer these questions through research, usually as part of postgraduate degree programmes. The science-shop model has proved quite successful in breaking down barriers between the research community and the public, as well as fostering a research-friendly culture among many of the advocacy groups and non-governmental organisations that originally commissioned work from them; indeed, many now have in-house research capacity (Farkas, 1999).

Relatively limited engagement of patients and service users during the actual process of research has, however, been a hallmark of the science-shop model. In comparison with other forms of community-based research elsewhere, science shops have been participatory only insofar as they have involved consumers in formulating research questions.

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[13] The Women's Health Research Network's Web site provides details of the funding support offered for community-based research: http://www.whrn.ca/opportunities.html (as of September 1, 2008).

There have been moves more recently to integrate lay participants in the Netherlands more closely into the process of research along the UK model (see below). In the health field, these have been led by the national health research funder, ZonMw (Netherlands Organisation for Health Research and Development), which has published a series of documents outlining its commitment to participatory forms of research.[14]

5.4 Participatory research in the United Kingdom

The United Kingdom has, in many respects, led the way in promoting participatory research. To some extent, this reflects a high degree of institutional centralisation in the health system, which has enabled the NHS to drive changes in this area from above. Since 1996, this has been carried out through a programme funded by the UK Department of Health, and dedicated to promoting participation at both strategic and process levels (known as INVOLVE). The programme, currently run by the National Institute for Health Research, was established to "promote public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used".[15] It provides an advisory and supporting function for health researchers in the United Kingdom, and has produced publications on everything from training for service users and researchers (Lockey et al., 2004), to guidance on how to build effective user-controlled projects (Turner and Beresford, 2005). Institutional support from the UK Department for Health and NHS has been reinforced through a number of strategic documents, including several emerging from the R&D programme (e.g. NHS Executive, 1999).

Non-profit research funders are also displaying a growing interest in participatory research following the lead set by the Department of Health and NHS. The National Association for Colitis and Crohn's Disease, for example, has a well-developed system for incorporating lay members into its grant peer-review process (AMRC, 2006).

However, by contrast with experiences elsewhere, there is evidence of a much greater range of participation levels in the United Kingdom, with patients and service users controlling the research process in some cases. Indeed, the findings of a recent study suggest that patients and service users may be involved in managing health research projects in 60% of those supported by UK funding bodies (O'Donnell and Entwistle, 2004b). The Strategies for Living programme run by the Mental Health Foundation is a case in point; this three-year national, voluntary sector research project was actively led by a consumer group, with a user consultant conducting much of the research during the initial phases of the project (Mental Health Foundation, 2000). The Alzheimer's Society Quality Research in Dementia programme also featured extensive patient and service-user involvement, this time on a collaborative model, as well as providing training to consumers involved in the project (Oliver et al., 2004). In these cases, lay participants are simultaneously involved both strategically and in the research process itself.

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[14] ZonMw, "News: Public Involvement at ZonMw, August 2, 2007", http://www.zonmw.nl/en/organisation/news/news/item/public-involvement-at-zonmw/ (as of September 1, 2008).

[15] NHS INVOLVE , "About INVOLVE", http://www.invo.org.uk/About_Us.asp (as of September 1, 2008).

Finally, participatory research methods seem to be winning greater favour from within the research and medical practice communities. The Royal College of Psychiatrists, for example, now routinely involves patients and service users in health services research through its Centre for Quality Improvement. It has also published a quality assurance checklist to govern the interaction between researchers and consumers, to ensure that the relationship is equitable and mutually advantageous.[16]

5.5 Participatory research in the United States

In the United States, by contrast, the record of lay participation in health research is patchier. As in the other countries we have examined, historical and social drivers for increased participation in health research have been strong in the United States. An important example has been the field of AIDS research, in which the central role of activists and CSOs in strengthening the case for lay involvement is well documented, and eventually reformed the way in which clinical trials were conducted (e.g. Epstein, 1995). Overall, a wide variety of actors are involved in promoting participatory research to a greater or lesser extent, and in often quite different ways.

An interesting feature of the community-based research landscape in the United States has been the extensive involvement at the strategic level of philanthropic organisations in large-scale funding and support for this approach (Minkler et al., 2003). The W. K. Kellogg Foundation, the Ford Foundation, the Annie E. Casey Foundation, and the Aspen Institute are among those bodies that have provided large amounts of financial support for participatory research in the United States. Some of these bodies also have an increasing role in promoting participatory research as an end in itself. For example, the California Endowment and the Public Health Institute both publicly support participatory evaluations of their programmes.

The extent of government involvement has been variable. On the one hand, government funding has had a particularly important role in promoting community-based research in the United States at the strategic level, certainly relative to private donations. Thus, the Centers for Disease Control and Prevention currently funds three urban research units specifically focused on participatory research methods, whereas the NIH has supported the formation of a network of Breast Cancer and the Environment research units around the country (currently with four primary centres and 10 smaller satellites).[17] On the other hand, government support for participatory research processes is arguably not as formalised in terms of guidance and regulation as found in some other countries, particularly in the United Kingdom. This is perhaps because of the high level of decentralisation in the U.S. health-care system. Whereas some key government agencies do show an increasing interest in patient and service-user involvement, this tends to be at a strategic level, with examples including the NIH and Agency for Health Research and Quality. Lay involvement in strategic matters at the NIH is mediated mainly through the Director's COPR. The recent launch of a Partners in Research programme at NIH, seeking proposals on innovative ways to advance lay participation in health research, suggests that the NIH's focus in this area may be shifting in new directions.[18] The Centers for Disease Control and Prevention has also recently published a set of principles governing community engagement with the research that it supports.

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[16] Royal College of Psychiatrists, "College Centre for Quality Improvement," http://www.rcpsych.ac.uk/researchtrainingunit/centreforqualityimprovement.aspx (as of August 31, 2008).

[17] For further details, see the Breast Cancer and the Environment Research Centers Web site: http://www.bcerc.org/index.htm (as of September 1, 2008).

Finally, participatory initiatives are particularly well developed in a few research fields, notably environmental health, social determinants, and mental health (as in other countries). This reflects increasing support from public health bodies in the United States, many of which advocate participatory approaches not only to core research issues, but also implementation and evaluation of interventions. A recently established academic–community-partnered research network in Los Angeles provides one example; this network included depression, psychological consequences of violence exposure in youth, obesity, and diabetes as lead research topics (Wells et al., 2006). Participatory approaches are also proving increasingly popular among those conducting research with military veterans (Kilbourne et al., 2008).

5.6 Lessons from the developing world: the role of CSOs

There is extensive literature on participatory research methods in developing countries, partly because this approach has been widely advocated by international development agencies for some years, in health research and more widely (McTaggart, 1997). Participatory approaches have been regarded as a necessary route if research results are to have any validity with respect to target populations, and if they are to win the support of these populations.

Several authors argue that CSOs can be a very positive force for change with respect to health research in developing countries. In particular, they see them as well situated to help address the 10/90 gap (Sanders et al., 2004). Several studies have identified particular research deficits with respect to (1) underlying health determinants, (2) health systems implementation, including individual and community service provision, and (3) strategies of social and behavioural change (Sanders et al., 2004).

What role might CSOs take in helping to bring about change? Some suggestions have been made (Bhan et al., 2007); in exploring these suggestions in greater depth, we can once again make a distinction between strategic- and process-level involvement. At strategic level, CSOs may act as community interfaces, thus creating valuable links between researchers and communities involved or potentially involved in research projects; this is particularly the case because many CSO staff come from the areas or communities that they represent. CSOs may also act as access points to vulnerable or stigmatised communities with which they have been able to build constructive relationships. They may act as touchstones, or points of reference for researchers seeking to test whether their proposed projects are in the best interests of the communities concerned. Importantly, they can have powerful roles as advocates for particular forms of research, or particular findings, although this can have important disadvantages. Finally, they may act as distribution channels, directly administering interventions based on health research beyond the reach of public and private health provision (e.g. in isolated rural areas). At the process level, of course, CSOs may conduct research themselves.

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[18] See press release accompanying the publication of the call for research proposals at http://www.nih.gov/news/pr/oct2007/od-23.htm (as of August 11, 2008).

Case study—Tenofovir: how poor handling of relations between researchers and lay participants has undermined a potentially powerful treatment

Whereas it is often assumed that increased participation in health research is inherently a "good thing", there are instances in which the activities of individuals or representatives has undermined the research process with potentially damaging results. One such example has been that of the antiretroviral drug tenofovir. Clinical trials for this drug have run into serious difficulties in several countries, but most notably in Cambodia and Cameroon, where trials have effectively been halted.

In theory, tenofovir promises significant benefits. The drug is regarded as a potentially effective pre-exposure form of prophylaxis for HIV among high-risk groups, and has been approved for use in the United States since 2001. Moreover, preliminary results with a small test group in three countries showed that tenofovir use does reduce infection rates.

However, the drug has been roundly attacked in several developing countries. The reasons for this opposition include the following: it is alleged that administrators of the trials have not provided sufficient prevention counselling to study participants; medical care has not been provided to those who became infected or who experienced adverse reactions during the course of the trial; and, perhaps most pertinently in this context, there was limited involvement for the trial communities in the design of the study. In particular, activist groups representing the patients involved charged that patients took most of the risks while seeing very few of the benefits in return. This reflects a wider concern over the level of engagement in the study design; although it seems that those running the trials did consult with host countries to ensure that they met the relevant ethical standards, the involvement of study participants was relatively limited.

As one observer of this episode recently concluded, "the rapidly collapsing tenofovir trial network shows that a lack of communication between activists, participants and researchers can lead to suspicion, speculation, and ultimately, damaging outcomes" (Singh and Mills, 2005).

Positioning CSOs as central to participatory approaches in developing countries is not without its problems. The high-profile failure of several recent research projects, including the abandoned trials in Cameroon and Cambodia for the antiretroviral drug tenofovir (see the case study below), demonstrates that CSOs may undermine potentially high-impact research work if relations between researchers and lay participants are not carefully handled (Tindana et al., 2007). Further questions have been raised over their legitimacy as representatives for community members (as they are elsewhere). Indeed, the emphasis on CSOs as the medium for participatory research and project work has in some quarters even been referred to as a new tyranny in the international development field, and one that may ultimately prove destructive by placing so much emphasis on a single kind of agent for participation (Cooke and Kothari, 2001).

Whereas assessments of the impact of participatory research projects in the developing world face many of the same problems as similar exercises elsewhere, leading international organisations in the health field are clear about the need to pursue this approach. In its flagship 2004 report on health research, *Knowledge for Better Health*, the World Health Organization outlined the importance of community participation in health research programmes in developing countries, describing it as “essential” (World Health Organization, 2004).

CHAPTER 6

What's next? Improving participatory health research methods

Headline points:

- Substantial improvements in the quality and impact of participatory research programmes in the future may be secured by agreeing a set of principles by which such research should be conducted.
- Improvements in training for both researchers and lay participants may have a particularly significant impact in improving research quality.
- Further evidence collection in this area is needed to support more thorough evaluations of the impact of participatory approaches on research outcomes.

The impetus towards greater patient and service-user involvement in health research is growing, not least in view of what might be called the quality agenda in health policy, and in practice more generally (Boaden et al., 2008). An important question, therefore, concerns ways in which current practices can be improved to ensure that participatory approaches are as efficient and effective as possible. To some extent, this may be achieved by adopting a more systematic approach to designing participatory research projects. A recent study has identified a set of principles and indicators of successful consumer involvement in NHS research, as outlined in Box 6.1.

1. The roles of consumers are agreed between the researchers and consumers involved in the research.
2. Researchers budget appropriately for the costs of consumer involvement in research.
3. Research respects the differing skills, knowledge, and experience of consumers.
4. Consumers are offered training and personal support to enable them to be involved in research.
5. Researchers ensure that they have the necessary skills to involve consumers in the research process.

6. Consumers involved in decisions about how participants are both recruited and kept informed about the progress of the research.
7. Consumer involvement is described in research reports.
8. Research findings are available to consumers, in formats and languages that they can easily understand.

SOURCE: Adapted from Boote, Barber, and Cooper, 2006.

Box 6.1—Questions that researchers should consider when designing a participatory project

Ultimately, the first of these points is probably the most important. It is imperative that each of the parties involved in research—whether at the strategic or process level—is clear about how, why, at what level, and at what point lay participants are likely to be involved. This chapter outlines two key areas in which our existing knowledge could be strengthened, while acknowledging the need for further evidence of what works across the board.

6.1 Improving the representativeness of patient samples

We have seen that a common criticism of patient and service-user involvement in research is that those who volunteer for it tend to be self-selecting: educated, often middle-class, patients, and patients' representatives or activists. A key issue in research design, therefore, is to find ways to ensure the representativeness of patient samples, mindful that trade-offs will always to some extent be required in this area (see section 4.2). One method that has been suggested is active incentivisation of participation by researchers or research funders. This might, for example, involve the paying of potential participants (Lockey et al., 2004). Evidence on the effectiveness of paid incentivisation is slim, but there is a strong sense from some studies that it may be beneficial.

6.2 Improving the training regime for lay participants and researchers

A recent review of practices in the United Kingdom made some important findings in terms of the effectiveness of lay-participant training programmes. The reviewers found that training was perceived as most useful when processes of exchange between participants and researchers were fully integrated into the programmes being offered, and where service users were given the space to make creative contributions to training design (Lockey et al., 2004). They also found that substantial time and effort needed to be allowed for training for all participants to make a full contribution; project timescales and funding allocations need to reflect this. Importantly, they found that well-run training significantly improved the readiness of lay participants to contribute in discussions on their research projects, mainly as a result of improved confidence with jargon and technical material. On this basis, it would seem that properly constructed training programmes should be integral to any participatory research project, but further research will be needed if we are to understand what particular forms of training are most effective.

6.3 Improving the evidence base around participatory research

The literature on participatory research is often politicised, reflecting a historical evolution that has often rested as much on social drivers and political and philosophical stances as on practical advantages. Although our understanding of the advantages and disadvantages of different approaches to participatory research is improving, further evidence gathering around the impact of different approaches will be needed. This effort will need to engage with some of the particular problems involved in the evaluation of participatory research. First, it is not immediately clear how we can measure levels of lay involvement in research (Boote, Telford, and Cooper, 2002). Second, despite the call for more randomised controlled trials of participatory methods, it is not clear how these would be set up and run (Fudge, Wolfe, and McKevitt, 2008). Finally, we have seen that different people tend to have very different perspectives on research, which makes evaluation efforts more difficult (Contandriopoulos, 2004).

Besides the issue of evaluation, several authors have identified areas in which further background research is needed (Boote, Telford, and Cooper, 2002; Oliver et al., 2004). First, questions remain about the further conceptualisation of issues such as consumer involvement and representation: are there alternative ways to understand participation in health research, and what might they be? What does it mean to be an effective representative in participatory research? This is particularly relevant at the interface between individual participatory methods and community participatory approaches, which are themselves linked. Second, more evidence is needed around the potential for improving the outcomes of participatory approaches, whether through improved understanding of trust between lay participants and researchers, or the way in which research findings are shared and disseminated.

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