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**Health Technology Assessment
NHS R&D HTA Programme**

HTA

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NHS R&D HTA Programme

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The research reported in this monograph was commissioned by the HTA Programme as project number 97/19/02. As funder, by devising a commissioning brief, the HTA Programme specified the research question and study design. The authors have been wholly responsible for all data collection, analysis and interpretation and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the referees for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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Abstract

Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach

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Objectives: To look at the processes and outcomes of identification and prioritisation in both national and regional R&D programmes in health and elsewhere, drawing on experiences of success and failure. Also to identify the barriers to, and facilitators of, meaningful participation by consumers in research identification and prioritisation.

Data sources: Electronic databases and interviews with UK consumers and research programme managers.

Review methods: A framework was devised for examining the diverse ways of involving consumers in research. It identified key distinguishing features as: the types of consumers involved; whether consumers or researchers initiated the involvement; the degree of consumer involvement (consultation, collaboration or consumer control); forums for communication (e.g. committees, surveys, focus groups); methods for decision-making; and the practicalities for implementation. Context (institutional, geographical and historical setting) and underpinning theories were considered as important variables for analysing examples of consumer involvement. This innovative framework was then applied to the review data from reports selected for inclusion and interviews.

Results: The study found 286 documents explicitly mentioning consumer involvement in identifying or prioritising research topics. Of these, 91 were general discussions, some of which included a theoretical analysis or a critique of research agendas from a consumer perspective, 160 reported specific efforts to include consumers in identifying or prioritising research topics and a further 51 reported consumers identifying or prioritising research topics in the course of other work. Detailed reports of 87 specific examples were identified. Most of this literature was descriptive reports by researchers who were key actors in involving consumers. A few reports were written by consumer participants. Fewer still were by independent researchers. Our conclusions are therefore not based on rigorous research, but implications for policy are drawn from individual reports and comparative analyses.

Conclusions: Productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices. The more that consumers are involved in determining how this is to be done, the more research programmes will learn from consumers and about how to work with them. Further success might be expected if research programmes embarking on collaborations approach well-networked consumers and provide them with information, resources and support to empower them in key roles for consulting their peers and prioritising topics. To be worthwhile, consultations should engage consumer groups directly and repeatedly in facilitated debate; when discussing health services research, more resources and time are required if consumers are drawn from groups whose main focus of interest is not health. These barriers can largely be overcome with good leadership, purposeful outreach to consumers, investing time and effort in good communication, training and support and thereby building good working relationships and

building on experience. Organised consumer groups capable of identifying research priorities also need to find ways of introducing their ideas into research programmes. Further research is suggested to develop and evaluate different training methods, information and education and other support for consumers and those wishing to involve them; to address the barriers to consumers' ideas influencing research agendas; and to carry out prospective comparative studies of different methods for involving consumers. Research about collective decision-making would also be further advanced by addressing the processes and outcomes of consensus development that involves consumers.

Contents

Glossary, list of abbreviations, and key

Technical terms and abbreviations are used throughout this report. The meaning is usually clear from the context, but a glossary is provided for the non-specialist reader. In some cases, usage differs in the literature, but the term has a constant meaning throughout this review.

Glossary

Bioethics   The study of ethical, social, legal, philosophical and other related issues arising in healthcare and in the biological sciences.

Collaboration   Active, on-going partnership. For example, partnership with consumers has included committee membership or less formal collaboration to complete a task, as in teamworking.

Community development   The process of involving a community in the identification and reinforcement of the aspects of everyday life, culture and political activity that are conducive to health. This might include support for political action to modify the total environment and strengthen resources for healthy living, and also reinforcing social networks and social support within a community and developing the material resources available to the community.

Consultation   As a method of involving consumers, asking consumers for their views and using these views to inform decision-making.

Consumers   Users and potential users of services, products and resources (including natural resources). In health this includes 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 programmes; and groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services. Depending on the context, consumers may also be described with any of the following terms: 'lay', 'non-expert',
'service user', 'survivor' or 'member of the general public'.

Descriptive reports (or descriptions)   Formal descriptions or reflections of, in this case, consumer involvement or of research management (including agenda setting).

Empowerment in research   Changes conventional research relations from inequality between active, dominant researchers and passive, subordinate research subjects to more equal relations between the two, and increased inclusion and involvement; the degree to which consumers are empowered to influence research may be evident in the source of the original research topics, the potential benefits and subsequent spread and use of research findings, the background and accountability of the researcher and the control of the research design, conduct and funding.

Evaluations   More than descriptions and reflections, in that they present clearly and systematically their methods of investigation and the results of the evaluation.

Involvement   Any form of participation in the making of decisions, at whatever stage or level, from consultation at the end of the decision-making process to joint working throughout the entire decision-making process.

Learning organisation   One in which people continually expand their capacity to achieve their objectives, where new and expansive patterns of thinking are nurtured and where people are continually learning how to learn together.

Glossary *continued*

Organisational change   Purposeful and reflective management of change within an organisation.

Participative research, participatory research, action research and participatory action research   Include collaboration, education and action. Such research stresses the relationship between researcher and community, with the direct benefit to the community as an outcome of the research and the community's involvement as itself beneficial.

Research and development agenda setting Identifying and prioritising topics suitable for research and development.

Research management   All stages from identification and prioritisation of research topics to conducting research and reporting and implementing the findings (e.g. evidence-based guideline development and evidence-based audit).

Consumer-controlled research   Consumers designing, undertaking and disseminating the results of a research project.

List of abbreviations

HEA	Health Education Authority (now Health Development Agency)	NPEU	National Perinatal Epidemiology Unit
IDDT	Insulin Dependent Diabetes Trust	PCD	physical and complex disabilities
NBCC	National Breast Cancer Coalition (USA)	PORT	Patient Outcomes Research Team (USA)
NCCHTA	National Coordinating Centre for Health Technology Assessment	R&D	research and development
NCT	National Childbirth Trust	RADAR	Society for Research in Rehabilitation
NEAT	New and Emerging Applications for Technology	RAGE	Radiotherapy Action Group Exposure
NIH	National Institutes of Health (USA)	SDO	service, delivery and organisation
NIOSH	National Institute for Occupational Safety and Health (USA)		

All abbreviations that have been used in this report are listed here unless the abbreviation is well known (e.g. NHS), or it has been used only once, or it is a non-standard abbreviation used only in figures/tables/appendices in which case the abbreviation is defined in the figure legend or at the end of the table.

Key

	Report written by non-participant observer	UK	Episode of involvement based in the UK
	Report written by consumers		Episode of involvement based elsewhere
	Report written by researchers		

Executive summary

Background

This is the first systematic study of consumer involvement in identifying and prioritising possible topics for research and development.

Objectives

The objectives of the study were to:

1. look at the processes and outcomes of identification and prioritisation in both national and regional R&D programmes in health and elsewhere, drawing on experiences of success and failure
2. identify the barriers to, and facilitators of, meaningful participation by consumers in the research identification and prioritisation.

Framework for examining consumer involvement

We devised a framework for examining the diverse ways of involving consumers in research. It identified key distinguishing features as: the types of consumers involved; whether consumers or researchers initiated the involvement; the degree of consumer involvement (consultation, collaboration or consumer control); forums for communication (e.g. committees, surveys, focus groups); methods for decision-making; and the practicalities for implementation. We considered context (institutional, geographical and historical setting) and underpinning theories as important variables for analysing examples of consumer involvement.

We translated the principles for minimising bias and maximising transparency to reviewing a body of literature that is largely descriptive or reflective rather than based on systematic research methods. We assumed, conventionally, that well-conducted research studies would be less biased and more reliable. In order to draw on other reports where necessary, we assumed that reports where consumers shared authorship with researchers would be less biased, that reports originating in

the UK would be more relevant and that findings supported by more reports or by reports originating from both the UK and elsewhere would be more generalisable.

Methods

We systematically sought literature through databases, handsearching and citation tracking, and also through people in the UK who were (a) known to have worked to identify or prioritise health research topics or (b) recognised consumer specialists or advocates.

We included reports if they explicitly mentioned consumer involvement in identifying or prioritising research topics. We also interviewed consumers and research programme managers from some UK examples. We applied the innovative framework to review data from interviews and reports.

Results

We found 286 documents explicitly mentioning consumer involvement in identifying or prioritising research topics. Of these, 91 were general discussions, some of which included a theoretical analysis or a critique of research agendas from a consumer perspective, 160 reported specific efforts to include consumers in identifying or prioritising research topics and a further 51 reported consumers identifying or prioritising research topics in the course of other work. We found detailed reports of 87 specific examples. These included:

- inviting consumer groups to collaborate in setting research agendas (13)
- consulting consumer groups (12)
- inviting individual consumers to collaborate in identifying and/or prioritising research topics (17)
- consulting individual consumers (13)
- responding to consumer action with a collaboration (13)
- responding to consumer action by consulting with consumers (3)

- responding to consumer action by conducting research without consumer input (6)
- consumers independently identifying or prioritising research topics (10).

Most of this literature was descriptive reports by researchers who were key actors in involving consumers. A few reports were written by consumer participants. Fewer still were by independent researchers. Our conclusions are therefore not based on rigorous research, but implications for policy are drawn from individual reports and comparative analyses.

Conclusions

Research programmes have sufficient collective experience of involving consumers to plan their agendas working directly or indirectly with consumers. Appropriate methods depend upon the tasks to be undertaken, the consumers to be involved and the support required. Productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices. The more that consumers are involved in determining how this is to be done, the more research programmes will learn from consumers and about how to work with them.

More success might be expected if research programmes embarking on collaborations approach well-networked consumers and provide them with information, resources and support to empower them in key roles for consulting their peers and prioritising topics. To be worthwhile, consultations should engage consumer groups directly and repeatedly in facilitated debate; when discussing health services research, more resources and time are required if consumers are drawn from groups whose main focus of interest is not health.

Barriers to consumer involvement include: poor representation of consumers; consumers' unfamiliarity with research and research programmes' unfamiliarity with consumers; negative attitudes and poor working relationships; difficulties in communication; and time constraints. These barriers can largely be overcome with good leadership, purposeful outreach to consumers, investing time and effort in good communication, training and support and thereby building good working relationships and building on experience.

Organised consumer groups capable of identifying research priorities need to find ways of introducing their ideas into research programmes. They should be aware that consumers making efforts to (re)design structures and procedures have had greater influence over research agendas. Consumers are particularly well placed to reflect on their experience of research agenda setting in order to build the evidence about their priorities and methods for involving them.

Recommendations for research

The following areas are recommended for further research.

- Research to develop and evaluate different training methods, information and education and other support for consumers and those wishing to involve them.
- Research to address the barriers to consumers' ideas influencing research agendas.
- It is suggested that research programmes embarking on working with consumers do so with a view to learning more about these processes using an ethos of reflexive research. At a minimum they should involve consumers in reflecting on and reporting the process and outcome. Whenever possible, they should involve consumers in considering the methods and implications of working together both in advance and with hindsight. There is also a place for independent researchers to work with research programmes and consumers to investigate and record working practices. Consumers should be involved in conducting and reporting this work.
- We suggest carrying out prospective comparative studies of different methods for involving consumers.
- It is suggested that research about collective decision-making be further advanced by addressing the processes and outcomes of consensus development that involves consumers.

Chapter 1

Introduction

Background

Setting research agendas is a specific aspect of priority setting. Hence, this study focuses on the intersection of priority setting and consumer involvement in research and development. Since 1990, priority setting for services in the NHS has generally become more explicit and has more commonly involved consumers. Since 1991 this has also involved the newly established NHS research and development (R&D) strategy.

Priority setting in NHS research

Traditionally, setting priorities for healthcare has been implicit in the decisions made by clinicians for their patients. In the UK, more formal and explicit methods were called for with the introduction of the internal market in 1991. This required purchasers of healthcare to act on behalf of the populations they served: taxpayers and patients. Justifying their decisions required developing explicit methods for priority setting.

Similarly, priorities for research were set in an uncoordinated fashion by academics and industry. The launch of the NHS R&D programme, also in 1991, provided a needs-led programme of commissioned research that counterbalanced the responsive programmes which relied primarily on researchers suggesting potential research projects to funders.[1] This was the beginning of a "systematic approach to identifying and setting R&D priorities in which NHS staff and the **users** of the Service are being asked to identify important issues which confront them and, in partnership with the research community, to characterise and prioritise these problems as the basis for seeking solutions"[2] [emphasis added]. This approach has evolved through a series of agenda-setting exercises by multidisciplinary advisory groups, some of which have involved consumers.

Consumer involvement in health services research

The NHS R&D strategy is committed to involving consumers in the work it undertakes – not as 'subjects' of research, but as active participants. The Central Research and Development Committee (which advises the Director of R&D) set up a unique group to advise them on how best to involve consumers in the R&D process. This group, which met for the first time in 1996, at the time of the study was called Consumers in NHS Research (it is now known as INVOLVE). It aims to ensure that consumer involvement in R&D in the NHS, public health and social care improves the way in which research is prioritised, commissioned, undertaken and disseminated.

Consumers may be involved in research because the NHS is politically mandated to involve those most intimately affected (the users of health services) and those who provide the funds, either directly or through taxes or insurance. They may also be involved because their experience and insights can complement those of health professionals and researchers, so that collectively these people can produce 'better' research. 'Better' research may be research that: has a higher methodological or ethical quality; produces findings which are more relevant to practical decisions made by consumers and those caring for them; is presented in more accessible and widely disseminated reports; or more appropriately influences policy and practice.

Consumer involvement in identifying and prioritising research topics should be considered in the context of the increasing involvement of consumers in making decisions about their own personal healthcare and about the development and delivery of services. Pressure for this increasing involvement comes from individual patients and service users, their families and carers, and from organised groups of such people.[3] Between them, these individuals and groups challenge the professionally dominated social structure of healthcare. They challenge indirectly, by using and developing alternative services within the voluntary or commercial sectors, and directly, by calling for change in established/statutory services, during clinical encounters, through complaints procedures and by campaigning.

With policy support for consumer involvement in research, and guidelines prepared on the basis of the pooled experience of consumers, academics and NHS staff by the Consumers in NHS Research group,[4] there is increasing interest and activity in this area. This was reflected in a special issue of

the *BMJ* in September 1999. The articles in this issue illustrated the extent of consumer involvement in health. They included opinion articles about consumer involvement in health services, research articles about patient involvement in shared decision-making in clinical settings and an interpretative review about participative research. However, there were no details about methods for involving consumers in identifying or prioritising research topics.

Research questions

This study aimed to review such literature as there is on consumer involvement in setting research agendas, to cover the health research field but also going beyond it. The review was required to record what methods have been attempted, for what purpose, how they have been evaluated and what can be learnt from their documentation and/or their evaluation.

Options for drawing on related literature beyond the immediate focus of the review included literature about: consumer involvement in evidence-based health decisions generally; consumer involvement in research apart from agenda setting; priority setting in health services; and research agenda setting in other sectors. The relevance and usefulness of each of these literatures was considered before defining the scope of the review, as described below.

The literature is most advanced for consumer involvement in evidence-based decision-making for personal healthcare, where there are well-established methods for consumer involvement and its evaluation[5] and a growing collection of systematic reviews of impact.[6] Other appraised and synthesised literature addresses eliciting public preferences, but not involvement in service decisions;[7] consensus development for clinical guidelines, but not involvement of consumers;[8] and priority setting for health services.[9] Despite their convenience, these publications were dismissed for being insufficiently relevant to consumer involvement in agenda setting which requires engagement with:

- organisational decision-making
- research methods
- gaps in knowledge, which is conceptually more challenging than engaging with gaps in services.

The literature about consumer involvement in research more broadly (i.e. not restricted to

research agenda setting) is extensive. It includes numerous reports of individual initiatives and traditional reviews, but no conveniently appraised and systematically synthesised summary or a widely agreed characterisation of the diverse methods for consumer involvement or their evaluation. This literature was therefore dismissed for being potentially overwhelming and in need of a systematic review independent of this project.

Ultimately, it was decided that the nature of research agenda setting set it apart from these other activities and their literature, that the act of prioritising gaps in knowledge, along with the technical nature of that knowledge, distinguished it from involvement in service provision decision-making and in other aspects of research.

There were therefore no restrictions applied in terms of the health sector, or other sectors, and the review's scope was therefore broadened to encompass research agenda setting in other sectors in order to answer the research question:

- **What are the advantages and disadvantages of different methods of involving consumers in identifying and prioritising possible topics for R&D?**
  The objectives of the study were to:
  1. look at the processes and outcomes of research identification and prioritisation in both national and regional R&D programmes in health and elsewhere, drawing on experiences of success and failure
  2. identify the barriers to, and facilitators of, meaningful participation by consumers in research identification and prioritisation.

In order to address these research questions, we brought together a research team of nine people including two consumers. In addition to formal roles in consumer organisations, academia and public health, as authors of this report we brought direct experience as consumers and researchers involved in research agenda setting. We subscribe to the belief that research agendas should reflect the needs and values of the people who use and pay for health services, and that this is unlikely to be achieved without directly involving some of these people. Our experience of consumer involvement in research has introduced us to many challenges and a few successes, but it has not led us to conclude that particular methods are reliably beneficial whatever the context.

Chapter 2

A framework for examining consumer involvement in research

This chapter proposes a framework for examining consumer involvement in research. It provides definitions for key concepts to help further define the scope of this review. It identifies key distinguishing features of different methods of consumer involvement and structures these into a framework for describing and analysing reports of specific episodes of consumer involvement. It finishes by discussing the applicability of principles for minimising bias and maximising transparency to reviewing a body of literature that is largely descriptive or reflective rather than based on systematic research methods.

Definitions

Consumers

The Consumers in NHS Research group recommended the following definition of consumers of healthcare. Consumers 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 programmes; and groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services.[4] In order to draw on other sectors (e.g. commercial and agricultural), we have extended this definition to include users and potential users of resources, including natural resources.

Research agenda setting

Research agenda setting includes both identifying and prioritising research topics. Although there are formal methods for both activities, reports of other activities such as collaborative service planning or environmental campaigning reveal examples of consumers identifying research topics in the course of those debates. For instance, gaps in evidence may be identified opportunistically when planning services, although they may not necessarily be captured in a useful way to inform a research agenda. We labelled this as opportunistic agenda setting, as opposed to purposeful agenda setting.

There is a similar distinction in prioritising research topics. Prioritising research topics may be purposeful in a formal agenda setting exercise, particularly for commissioned research programmes. Alternatively, prioritisation may be an amalgamation of researchers' priorities and the responses of peer referees and funding panels, as is more common where funders respond to unsolicited proposals from researchers (responsive programmes). Lastly, consumers may identify principles for prioritising topics, without necessarily being involved directly in prioritisation. We have included all these activities in the scope of our review as they are all aspects of research agenda setting.

Consumer involvement

Consumers involved in research have traditionally been given the role of research 'subject'. An alternative role requires more active involvement in guiding the research rather than merely providing data. In this review, our interest is in consumers providing their views in order to influence research. We have included reports of purposeful agenda setting where consumers have been actively involved, where they have consulted or where they have been involved indirectly through other activities (such as asking questions in Parliament or to helplines). We have also included reports of consumers being involved opportunistically in identifying research topics, such as women raising research issues in the course of campaigning for better maternity services.[10] We have not included most of the research literature where consumers are subjects and researchers conclude their analyses with recommendations for further work.

Characteristics of consumer involvement in research agenda setting

Describing reports of consumer involvement in research agenda setting coherently and consistently was a challenge that we struggled to overcome throughout the duration of the study. Consumers have been involved in many types of

research through a diversity of methods. The names of particular activities appear to label them without providing a consistent system for distinguishing them. For instance, the Cochrane Consumer Network emphasises (with the name of Cochrane) its central importance of contributing to systematic reviews, whereas the National Breast Cancer Coalition of member organisations is named according to the health condition in which they share an interest. In contrast, participative research initiatives[11] and community participation and development often employed in health promotion[12,13] are identified by their underlying philosophy rather than their specific interests. In seeking to identify the advantages and disadvantages of different methods, we needed to set aside labels of specific examples commonly and conveniently used in discussions, and describe methods in terms that would distinguish examples in meaningful ways.

We sought distinguishing characteristics of different methods for involving consumers in research agenda setting from our own experience, current policy documents, abstracts of relevant literature, key methodological literature and related systematic reviews.

We chose as key features for our framework those characteristics which we assumed would influence the process and outcome of consumer involvement: the consumers involved, who initiated the involvement, the degree of involvement, the forum for exchanging ideas and the methods for decision-making. Each of these is considered below.

Consumers involved
The definition of consumers provided above is broad. Although there are clearly important differences between patients, carers and the broader public, for the purpose of reviewing methods for involving consumers, we recognise the most pertinent distinction being between people involved as individuals and people involved as members of organised consumer groups. Members of organised groups are not typical of the general public. In being a member of a group they have expressed an active interest and, potentially, they have access to a broader range of views than those formed by their own experience alone. Another overlapping distinction is between consumers who have volunteered their involvement (for instance, through their membership of a group or by responding to an advertisement) and consumers who have been targeted for involvement (for instance, through

representative opinion polls). These distinctions are analogous to distinctions between health professionals who volunteer to represent their peers in consultations or formal reviews about professional practice and experience and those who have been targeted for their involvement. Similarly, there is a distinction between health professionals who express an active interest in research and those who do not despite current policy supporting research-based practice.

Proactive and reactive involvement
Consumer involvement can be an expression of consumer empowerment. This empowerment can be initiated in specific encounters between consumers and professional services by either party and this affects not only how involvement has developed, but also how this involvement is viewed by health professionals and by different sectors of society.[14]

Where researchers or research programmes have taken the initiative, they may be embarking on an exercise in organisational change where theories about learning organisations highlight the importance of inclusion, reflection and managing diversity.[15,16] An alternative theoretical approach is participatory research, which probably requires the greatest changes in organisational structures and procedures and is claimed to maximise community and lay involvement.[17] The three primary features of participatory research include collaboration, mutual education and acting on the results developed from research questions that are relevant to the community. It therefore embraces more of the research to service pathway than merely research agenda setting.

Consumers taking the initiative was part of a broader collective social action, where campaigns and self-help groups emerged in response to health problems to engage in research under their own initiative. In these circumstances, self-help groups or other social service or political advocacy groups act as social movement organisations.[3]

Degree of involvement
The extent to which consumers can influence decisions rather than just be aware of them depends on their degree of involvement. Arnstein proposed a 'ladder of participation' with rungs on the ladder representing increasing degrees of participation, from non-participation or manipulation and therapy, through the tokenism of informing, consulting and placating to citizen power through partnership, delegated power and citizen control.[18] She described contrasting

examples in America of frequent 'attitude surveys' in ghetto neighbourhoods where residents see their time being taken up for no benefit, and residents elsewhere being delegated and funded the power to prepare an entire 'model cities' plan. This ladder of participation has been contracted to three steps by Consumer in NHS Research: consultation, collaboration and consumer control.[4] We anticipated finding examples of consultation, collaboration and consumer control in research agenda setting and adopted this terminology for our framework.

- **Consultation** was defined as asking consumers for their views and using these views to inform decision-making. For example, funders of research have held one-off meetings with consumers to ask them about their priorities for research, or write to consumers in accessible terms to invite their views. Consumers' views were not necessarily adopted, although they may inform decisions.
- **Collaboration** was described as active, on-going partnership with consumers. For example, consumers have been committee members or collaborated less formally to complete a task.
- **Consumer-controlled research** was described as consumers designing, undertaking and disseminating the results of a research project. 'Professionals' were only involved at the invitation of the consumers.

Consultation, collaboration or consumer control, defined as above throughout this report, have been used at different stages of the same projects.

Forum for exchanging ideas
However a working relationship has been initiated, and whatever the degree of involvement, there are also many options for the type of forum for exchanging ideas. The choice of forum will be determined by the type and range of tasks on which consumers and others are embarked. A recent review of public involvement in healthcare priority setting described how methods for engaging consumers in collaborations or consultations have been chosen for different purposes.[9] The authors distinguished qualitative methods such as one-to-one interviews, focus groups, Delphi technique and citizens' juries, which elicit ideas, from quantitative methods such as ranking or rating, which set priorities.[19]

Methods for decision-making
These methods for engaging in a working relationship can vary further in the way in which decisions are made. Methods that support

collective decision-making include those for eliciting values (such as voting, ranking, scoring, visual scales and Delphi surveys) and those for aggregating values. A systematic review of consensus development for clinical guidelines drew a number of conclusions which might be applicable to research agenda setting.[8] These conclusions related to selecting the participants, choosing and preparing background information, structuring the interaction and synthesising individual judgements. However, few of the studies specifically related to consumers.

Implementation
The final details of any methods are the practicalities of implementation. These can include planning, resources, coordination and training. We anticipated, for example, that dedicated resources or training materials would lead to greater consumer influence. How methods are implemented may facilitate or hinder consumer involvement. For instance, attention to the facilitation of multidisciplinary groups, as advised by Consumers in NHS Research, is likely to affect the extent to which consumers are able to express their views and be heard.[4]

Context of consumer involvement in research
As we became more familiar with the range of examples of consumer involvement in setting research agendas, we encountered more contextual issues, which we considered were likely influences of how methods developed and how appropriate or successful they appeared to be. We recognised contextual issues that were associated with the consumers and the researchers involved, particularly the organisational setting of the players (see *Box 1*). These included institutional settings (e.g. academic or commercial research or self-help or charitable voluntary sector organisations), geographical settings (e.g. regional, national, international), and historical settings in relation to rights movements (e.g. with or without a legacy of consumer activism).

Theories underpinning consumer involvement

Similarly, our understanding of the role of theory in investigating consumer involvement advanced as we became more familiar with the diversity of methods and circumstances of consumer involvement. We recognised (see above) that different initiators of consumer involvement are likely to have different motivations and different

methods of working. For instance, forward-looking research programmes have employed an organisational change approach to management whereas forward-looking consumers have employed collective social action. A diversity of theories relate to how consumers are involved (see *Box 2*). For instance, a framework of evidence-

informed patient choice invokes attention to patients' questions in order to identify research questions.[5] Alternatively, community development invokes recognising research topics in the course of working with communities in order to identify their own health needs and support them in taking action to address them.[12,13] On a broader scale still, bioethics brings ethical, social, legal and philosophical perspectives to public debates about health services and related research.[20]

The research programme:
- the research focus (e.g. topic focus and type of research)
- organisational setting of the research programme (e.g. geographical scope and nature of funding body)
- experience and resources for consumer involvement.

The consumers:
- focus of interest (e.g. services, population, patients or carers)
- function of group (e.g. campaigning, mutual support)
- organisational setting of the consumers (e.g. geographical scope of group)
- experience and resources for involvement in research.

The interaction
- initiated by research programme or by consumers
- methods employed to involve consumers in identifying or prioritising research topics
- tasks undertaken by consumers
- relationship between consumers involved and wider consumer population.

BOX 1 *Characteristics of players and methods for interaction – framework for selecting UK cases*

Evaluating consumer involvement

Advantages and disadvantages

The main reasons for involving consumers are pragmatism, in the face of consumer demand or non-cooperation, political principle and the pursuit of 'better' research. The principles and practicalities of consumer involvement may be satisfied by the presence of consumers during the planning process, and the quality of their involvement in those processes may be a measure of success. These can be considered as intermediate benefits or, when success is not assured, intermediate harms and costs. The objective of better research has a range of more ambitious interpretations. 'Better' research could mean methodologically or ethically superior research, or research that is more likely to influence practice and improve health. Some of

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- Bioethics (the study of the ethical, social, legal, philosophical and other related issues arising in healthcare and in the biological sciences.[20]
- Collective social action (where people join forces with the aim of improving lives through campaigning and peer support).[3]
- Community development is the process of involving a community in the identification and reinforcement of the aspects of everyday life, culture and political activity that are conducive to health. This might include support for political action to modify the total environment and strengthen resources for healthy living, as well as reinforcing social networks and social support within a community and developing the material resources available to the community.[12]
- Consumerism (where the motivation for involving consumers is financial and consumers are seen as direct users of a commercial product).[75]
- Empowerment in research changes conventional research relations from inequality between active, dominant researchers and passive, subordinate research subjects to more equal relations between the two, and increased inclusion and involvement; where service users play a greater part in identifying the topic for research and the benefits of research, designing and conducting the research, disseminating and acting on the research findings, and having more control over the funding and the research process.[21]
- Evidence-informed patient choice (where the interests of patients are framed in terms of evidence required to support personal health decisions).[5]
- A learning organisation is one where people continually expand their capacity to achieve their objectives, where new and expansive patterns of thinking are nurtured, and where people are continually learning how to learn together.[16]
- Managing diversity (where methods were adapted specifically to encourage input from populations who might otherwise find existing structures and procedures too great a barrier).[15,16]
- Organisational change (where there was an intention within an organisation to develop new formal methods through piloting and reflection).[15,16]
- Participatory research (where collaboration, education and action combined to enhance the relationship between researcher and community, with direct benefit to the community as an outcome of the research and the community's involvement being itself beneficial).[17]

BOX 2 *Theories of consumer involvement in research or service planning*

this better research may be better because it better fits the needs of an important and arguably under-represented stakeholder group. These objectives can be considered as final benefits or, if not met, final harms and costs (such as lack of research, poorer research, opportunity costs and bad publicity).

The degree to which consumers influence research may be evident in the source of the original research topics, the potential benefits and subsequent spread and use of research findings, the background and accountability of the researcher and the control of the research design, conduct and funding.[21] For instance, plans for a conventional survey by a researcher of disabled people using cash payments provided by the Independent Living Support Service was challenged by the service users obtaining funding and directing a piece of research themselves, with the help of a professional researcher as a consultant, thereby controlling the presentation of the findings and their use in future decisions about funding.[22]

Based on their collective experience of consumers, practitioners and researchers, Consumers in NHS Research attributed advantages and disadvantages to different degrees of involvement.[4] The advantages of consultation were seen as obtaining consumer views quickly without being committed to act on them and being a 'safe' way to start working with consumers. Disadvantages were also recognised. Some consumers have found it frustrating to be asked their views without any commitment to act on them. Some consumer organisations have declined to become involved, arguing that it is a waste of their time if they are not seen as partners in the research process, particularly if their views had been ignored in the past. The advantages of collaboration were seen as increasing the likelihood that the outcome measures, assessment criteria and evaluation would be relevant to consumer participants in research, access to consumers as research participants would be improved and consumers could help with recruitment and informed consent, and with interpreting and understanding data. Following collaboration, consumers were likely to feel more ownership of research results and be more likely to actively disseminate them. The perceived disadvantages included the additional time, costs and possible alienation. This approach involved an active commitment to collaborate, which meant that some control over the research was lost by the researchers. The perceived advantages of consumer-controlled

research included increased involvement of consumers who have often been marginalised, research likely to address questions that may not have been considered important to researchers and the development of research skills among consumers and the professionals with whom they worked. Commitment from consumer organisations to disseminate the results of research and to influence change in practice was considered more likely. This type of involvement requires researchers to hand over the ownership of a project to consumers. Some researchers have found this difficult or unacceptable.

Box 3 lists outcomes and processes that may be assessed in attempts to evaluate consumer involvement in setting research agendas. These include recording participants' views on the process, demonstrating changes in the process and consumers' consequent influence on the research, and subsequently on healthcare and health. The remit of this study is limited to investigating the processes of research agenda setting and consumer influence on the research agenda. The importance of a benefit or harm may be perceived differently by researchers and by consumers. For instance, greater uptake of research findings may be welcomed by a profession embracing evidence-informed practice, but not by consumers who are critical of the original research.

Advantages and disadvantages of methods may also be conceived not as measures of achievement, but as features that facilitate or hinder consumer involvement. For instance, good communication or skilled facilitators may benefit consumer involvement, whereas short timetables or technical language may hinder it.

Hence an advantage or disadvantage may be perceived as a facilitator of, or a barrier to, agenda setting or consumer involvement, a benefit, or cost resulting from agenda setting or consumer involvement, at an intermediate stage or as a final outcome, as seen by consumers or researchers.

A framework for analysis

Facing such a diversity of methods for consumer involvement, we needed an analytical framework for grouping similar episodes of consumer involvement, comparing similarities and differences between them and identifying common conclusions. From the concepts described above, we conceived a framework based on:

- whether consumers were involved as individuals or as members of organised groups
- whether the involvement was at the invitation of the research programme or in response to consumer action (approach to engagement)
- the degree to which consumers were involved (consultation, collaboration and user control).

This combined a simplified version of Arnstein's ladder of involvement[18] as operationalised by Consumers in NHS Research[4] and Mullen and

colleagues' distinction between reactive and proactive consumer involvement[14] (see *Figure 1*).

The columns represent decreasing consumer involvement and the rows represent decreasing researcher commitment to consumer involvement. Examining the different possible combinations would allow us to describe the methods that were employed to support such an engagement in terms of who was involved, how and with what consequences (as discussed above). When this

	Benefits	**Harms and costs**
Intermediate measures	More informed discussion between consumers and professionals. Greater understanding by consumers of technical issues. Improved sensitivity to consumer concerns in planning research. Reduced barriers to broad participation. Improved public profile of research. Increased credibility of consumers. Increased enthusiasm amongst consumers and professionals for working together. Consumer and manager descriptions of success in involving consumers in R&D.	Increased work load. Diverting consumers' efforts from services and campaigning. Decreased enthusiasm amongst consumers and professionals for working together. Greater confusion about the purpose of research. Damaged public profile of research. Reduced credibility of consumers. Lack of reporting of consumer involvement.
Final measures	Research incorporating consumers' ideas and addressing consumers' concerns and needs. Greater uptake of research findings. Improved care. Improved health.	Delayed research. More expensive research. Disappointment in limitations of research. Reduced uptake of research findings.

BOX 3 *Evaluating consumer involvement*

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A	Type B	
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

FIGURE 1 *Framework for describing consumer involvement in research agenda setting*

framework is illustrated as a table, some cells remain empty because they represent scenarios that are illogical or imply minimal engagement between the two groups. For instance, consumer-controlled action was unlikely to be initiated by research programmes (column 1, row 1), and research programmes cannot consult or collaborate with consumers if they are minor partners or absent (row 4, columns 2 and 3).

The details of methods applied within each type of approach to engagement were conceptualised as the operational methods of an episode of consumer involvement. Thus each type of engagement might have embraced one or more forums for discussion (e.g. committee membership, written consultation, focus groups or public meetings) that may have employed formal or informal methods for building consensus or other decision-making. We therefore needed to consider included specific interactions between consumers and research programmes in terms of both the approach to engagement and the operational methods of involvement.

In addition to the above five dimensions describing each model of interaction:

- consumers involved
- direction of approach
- degree of consumer involvement
- forum for exchange
- methods for decision-making

we hypothesised that the context (in terms of the research focus and the historical, geographical or institutional setting) would also be significant, as would the selection or self-selection of participant consumers. Together these provide a set of key variables for describing the diverse episodes of consumer involvement in research agenda setting.

Methodology

Typical of a newly developing area, research about consumer involvement is scant. Enthusiasts initially report their reflective descriptions, and research programmes report consumer involvement with little or no detail. Formal research, exploring or evaluating consumer involvement, is rare. In order to identify those methods that appear most advantageous, we applied the principles from systematic review methodology of maximising relevance, reliability and generalisability and minimising bias. We assumed, conventionally, that well-conducted research studies would be less biased and more reliable. In order to draw on other reports where necessary, we assumed that reports where consumers shared authorship with researchers would be less biased, that reports originating in the UK would be more relevant and that findings supported by more reports or by reports originating from both the UK and elsewhere would be more generalisable.

Chapter 3
Methods

This study had two main parts:

1. a systematic review of the empirical research literature about methods for consumer involvement in research agenda setting
2. a description of cases illustrating the range of methods used for consumer involvement in research agenda setting in the UK.

Part 1: systematic review of the literature

Searching

The full searching strategy is reported in Appendix 1. A brief description follows here. We interrogated commercially available and specialised bibliographic databases for references to literature at the intersections of 'consumer' involvement in decision-making, research and development and agenda setting. Database search strategies were developed by (i) using controlled and free-text terms and (ii) combining terms for consumer involvement with those describing research and development and agenda setting. Searches were made of commercially available bibliographic databases (MEDLINE, EMBASE, CINAHL, Social Science Citation Index and Applied Social Sciences Index and Abstracts) and specialised databases and registers [ERA, the EPPI Centre's in-house database of consumer involvement in research (http://eppi.ioe.ac.uk), and CAREDATA, from the National Institute of Social Work].

We handsearched conference reports and scanned web pages of R&D programmes. References of several reviews of consumer involvement were also searched for studies of possible relevance. Because details of consumer involvement in research agenda setting are often not reported, either in research papers or programme reports, we wrote to over 250 researchers and consumers. We identified them from NHS R&D programme reports and web pages, presentations about consumer involvement at conferences, records held by consumers and researchers working with them and references in reports and papers. We asked for information about potentially relevant episodes of consumer involvement and for other

contacts and related documents. Of these 250, 15 consumers and 57 researchers replied. All but one of these was from the UK.

Selecting reports for inclusion in the review

A set of inclusion criteria (*Box 4*) was used to identify studies to review in depth. A team of three researchers screened potentially relevant reports. In order to facilitate discussion of the inclusion criteria and their application, two researchers independently screened abstracts and titles found by searching bibliographic databases. Full copies of all relevant reports were retrieved. Where there was any doubt, researchers were over-inclusive and retrieved full reports. Once obtained, the full reports were screened by two researchers independently. Any discrepancies were resolved by discussion.

Reports meeting the inclusion criteria for the review could be original descriptions or formal studies of episodes of consumer involvement. Literature reviews of consumer involvement were not selected for in-depth review. Instead, they were used to identify primary reports, and the findings of reviews were included in the discussion of the current review.

Review of reports' content and quality assessment

Each report was then examined to identify and describe specific episodes of consumer involvement in research agenda setting. Where episodes were described in more than one report, information on each episode was pooled from all the relevant reports. Each episode was then described using the following structured summary format:

- A description of the episode in terms of each of the aspects required for inclusion criterion number 4 listed in *Box 4*; characteristics of the research programme concerned; the sort of consumers involved; the methods employed to involve consumers; the tasks consumers undertook; the roles consumers undertook; and an indication of the time frame for involving consumers.
- The theories underpinning this interaction where the characteristics of the aims, methods

To be included in the review[a], a report needed to meet all four of the following criteria. The report needed to:

1. be about the involvement of consumers, or an attempt to involve consumers
2. be about research agenda setting (or the identification or prioritisation of research topics)
3. describe one or more specific episodes of consumer involvement in agenda setting (as opposed to being, for example, solely a discussion of theory or methods for consumer involvement in research agendas or a description of a research agenda written from a consumer perspective)
4. report, in some way, about each of the following aspects of an episode
   (a) characteristics of the research programme concerned (reports needed to describe one or more characteristics of the programme defining its scope, such as its geographical boundary, research methods, or health topic focus)
   (b) the sort of consumers involved (reports needed to describe one or more defining characteristics of the consumers involved, such as their group identity, their primary function, or their geographical scope)
   (c) the methods employed to involve consumers (reports needed to describe how consumers were involved, e.g. through written consultations, committee membership, focus groups)
   (d) the tasks that consumers undertook (reports needed to describe whether consumers were involved in identifying and/or prioritising research)
   (e) the roles that consumers undertook (reports needed to describe how consumers related to their peers, e.g. whether they acted independently, or represented or consulted other consumers)
   (f) the time frame for involving consumers (reports needed to include when and for how long consumers were involved).

[a] Reports found to meet the first two, but not all four, of these criteria (i.e. discussions of consumer involvement in agenda setting not allied to a specific episode, or insufficiently detailed reports of specific episodes) have been coded so that they are available for further research.

BOX 4 *Inclusion criteria for literature review*

or context clearly indicated particular theories of involvement (as judged by the reviewers or, when included in reports, as described by the reports' authors) (see *Box 4*).

- The output (in terms of research topics identified or prioritised with or by consumers).
- Factors that advantaged (facilitators) or disadvantaged (barriers) consumer involvement and the advantages and disadvantages which ensued (outcomes and outputs).
- When facilitators or barriers, or outcomes and outputs were described, to what the reports' authors attributed them.
- The nature of the evidence, in terms of (a) whether the episode was examined with a formal study or was presented in a descriptive report, (b) whether those reporting it were independent of the episode or had been participants in the episode and (c) whether those reporting it did so from a consumer or research programme perspective.

These data were collated in tables to facilitate a qualitative analysis within each type of engagement.

Synthesis of findings

The findings were synthesised within the framework described in Chapter 2. This framework allowed us to describe and synthesise the findings from a large and disparate literature. It helped us to navigate the various approaches and operational methods of involvement and we have adopted this framework as a structure for the findings of this report.

The reports were synthesised in successive steps of summary and analysis. Reports were initially sorted into the types of approaches to engagement (A–H) depending on whether they were researcher or consumer initiated, and whether consumers were consulted, collaborators or in control. Within each type of approach, forums identified for exchanging ideas were listed (e.g. committee membership, teamworking, written consultations, face-to-face consultations, single or repeated consultations). The descriptions for these forums were not mutually exclusive, but were chosen within each type of approach in order to group similar episodes of consumer involvement.

Within each of these forums, individual episodes of involvement were briefly outlined in terms of the methods employed for identifying and prioritising research topics and the methods for involving consumers. These descriptions are also summarised in Tables 1–8.

After each forum, or forums combined in single episodes of consumer involvement, had been described and illustrated with specific examples, we highlighted what we considered could be learnt from this collective experience of each forum in a reviewer's commentary. Specifically, we noted those circumstances and attributes of the interaction (processes) that appeared to advantage or disadvantage consumer involvement (facilitators and barriers), and the advantages and disadvantages which ensued (outcomes and outputs). In an overview of each type of involvement, we listed our interpretation of what could be learnt from these data (our conclusions) as key messages relevant to each type of approach to engagement. These key messages were prioritised if they were drawn from reports written by consumers and researchers, or from more than one report, and considered widely applicable if they were drawn from reports prepared both in the UK and elsewhere. Following this analysis of each type of engagement, we conducted a qualitative synthesis of the findings based on a detailed comparison of the findings as they related to the different approaches to engagement, forum for exchange, methods for decision-making, context and underpinning theories (see Chapter 4).

Part 2: illustrating methods used in the UK

The authors' collective experience of consumer involvement in research includes working as consumers and as researchers and research commissioners on individual projects and programmes in the UK and internationally that actively involved consumers. From this experience of consumer involvement in research, we hypothesised about the variety of circumstances, researcher and consumer participants and methods of working that might be employed within the UK. We developed a classification to describe methods for consumers and research programmes to interact in setting research agendas (see *Box 1*).

The classification incorporated characteristics of both research programmes and consumers in terms of their research focus, their organisational setting and their ethos towards participative working and/or research. It incorporated characteristics of interactions between the two groups in terms of the relationship of consumers with their peers during the interaction, the tasks they undertook, the methods for interaction and the timescale. For instance, the NHS R&D programme could be characterised as national or regional programmes with a central focus on a specific condition (e.g. asthma or cancer) or broader tasks (e.g. health technology or primary/secondary care interface); with different funding mechanisms (e.g. commissioned or responsive programmes) and attitudes towards working with consumers (e.g. with or without experience and resources for supporting consumer participation in research). The consumers they interacted with might be identified by their roles (e.g. patients or carers), health or social conditions (e.g. Alzheimer's disease or homelessness), or populations (e.g. mothers and children or older people) and the primary function of the group (e.g. self-help, campaigning or charitable funding). The interactions between the research programmes and the consumers may have varied in how consumers are represented (e.g. individual patients, expert advocates or group consultation), the tasks they were involved in (e.g. identifying or prioritising topics, or offering general advice) and the routes for inputting their ideas (e.g. committee membership, written consultations, structured surveys, workshops/focus groups, drawing on literature/secondary data or unsolicited consumer suggestions).

This predetermined classification had two purposes. First, it was available for purposive sampling of episodes of consumer involvement to ensure that the illustrative cases addressed a diversity of experiences. Second, it was available to guide a narrative synthesis that could address the influence of diverse circumstances for consumer involvement (see Chapter 6).

We sought examples of consumer involvement in the UK in order to maximise the relevance of findings to research in the NHS. We sought examples of consumer involvement in R&D programmes which, between them, presented a wide variation in terms of the characteristics of the research programme, the consumers and the interaction (see *Box 1*).

We found 38 episodes of consumer involvement in research agenda setting in the UK that were reported in sufficient detail to include in the systematic review of the literature. Of these, we chose 11 to investigate in more detail, purposively selected to cover the range of characteristics which were thought likely to influence the aims, processes and outcomes of interactions between consumers and research programmes (as described in *Box 1*). To capture both consumer and programme perspectives, we selected some

episodes from consumer organisations that were involved more generally in research, and others from research programmes involving consumers.

For 10 of these episodes, a semi-structured telephone interview was held with at least one participant, usually more, including both consumer and programme representatives. (We were unable to interview researchers for one case or consumers for another and, for another case, data were taken from internal consumer group papers.) Interviewees were encouraged to describe, in their own words, methods used to involve consumers as part of the episode, the roles taken on by consumers, the kind of consumers involved and the length of time taken to develop consumer involvement. Interviewees were encouraged to discuss both positive and disappointing aspects of consumer involvement. We did this specifically to counterbalance the bias imposed by the greater attention we expected to find in the published literature to those examples perceived as positive. The interviews were taped, with the consent of each interviewee, and then detailed notes were made of each interview. Each interview was listened to by at least three of the authors, at least

one consumer and at least one involved in a research programme, in order to gain a broader range of views on themes arising. Themes identified from the interviews are presented in this report without reference to the individuals or organisations in order to maintain confidentiality.

Documents relating to each episode were requested from interviewees and others were identified by broader literature searches. These were added to the literature review and analysed as described in part 1, above.

For a more in-depth analysis, each episode was described in terms of the methods for identifying or prioritising research topics, the approach for engaging consumers in the task, the detailed methods of the interaction with consumers and the output of the programme. This was followed by consumer and research programme staff descriptions of their experiences and perceptions. We then analysed these data in terms of barriers and facilitators to consumer involvement, and advantages and disadvantages of methods for consumer involvement.

Chapter 4
Results of systematic review

Consumer involvement in research agenda setting

Some of the 286 documents that explicitly mentioned consumer involvement in identifying or prioritising research topics (see *Figure 2*) were general discussions. These included theoretical discussions of differing priorities, conceptual frameworks, community equipoise, power, democratic practice and advocacy and a manual for involving consumers, across a range of research topics including animal experimentation, organ transplants, human cloning and autism.

Of these 286:

- 23 were discussions of theory (e.g. empowerment) and/or process (i.e. methods for involving consumers in research agenda setting).
- 28 were records or analyses of research programmes or topics from a consumer perspective.

The majority of the 286 reports identified reported specific episodes:

- 160 related to specific episodes of efforts to include consumers in identifying and/or prioritising research topics – 'purposeful agenda setting'; 103 of these included sufficient detail for in-depth review.
- 51 reported consumers identifying and/or prioritising research topics while undertaking related work (e.g. health service development, voluntary sector development, campaigning) – 'opportunistic agenda setting'; 32 of these opportunistic episodes included sufficient detail for in-depth review.

Examples of purposeful and opportunistic agenda setting were found for specific:

- health conditions (asthma, breastfeeding, cancer, cystic fibrosis, dental health, diabetes, disfigurement, HIV, hyperactivity, learning difficulties, mental health, physical and complex disabilities)
- populations (older people, young people)

- interventions (physiotherapy, organ transplants, wheelchairs and other assistive devices)
- settings (homelessness, occupational health, school health, urban health)
- research methodologies (systematic reviews, technology assessment)
- disciplines (agriculture, genetics, environmental studies).

'Methods of involvement' described how either individuals or groups engaged with research programmes. Individuals were engaged as part of their clinical encounters where the questions they ask or the decisions they make about their own health problems and care inform research, through their use of complaints procedures or by invitation. They were also involved indirectly when their activities (e.g. choice of services or treatments) were analysed in order to inform research. Similarly, groups of consumers were engaged directly by responses to their campaigns or by invitation, or indirectly through analysis of their activities (e.g. their literature or alternative services). Specific interactions were initiated either by consumers or by research programmes and are described (as types A–H) below (see *Figure 1*).

All these documents varied in the strength of evidence they used for drawing conclusions. They either:

- described methods of involvement, with or without reflection, or
- reported formal studies of consumer involvement, where the research methods used to analyse the interaction were clearly reported.

Of these reports, all were descriptions of episodes except four that were reviews and six that were formal studies of specific episodes of consumer involvement that reported their methods of investigation. These methods varied from monitoring and requesting feedback on involvement to ethnographic study, and were reported with more or less detail. There are no agreed quality criteria for appraising the observational and qualitative study designs employed,[23] nor could we be confident that the formal studies, varying as they did in their methods and detail, were necessarily more reliable

Approximately 3800 citations found

Not about consumer involvement (*n* = 3149)

About consumer involvement in areas other than agenda setting (*n* = 367)
      e.g. in research outside agenda setting
      e.g. in developing priorities for services

About consumer involvement in agenda setting (*n* = 286):
      Purposeful (*n* = 160)*
      Opportunistic (*n* = 51)

Not a report of a specific episode (*n* =91)
      e.g. analyses of research agendas (*n* =28)
      e.g. theoretical discussions (*n* = 23)

About one or more specific episodes of consumer involvement in research agenda setting (*n* = 199)

Insufficient detail of agenda-setting episode (*n* = 76)

Detailed report of specific episode(s) of consumer involvement in research agenda setting (*n* = 135)

13 Type A: Research programmes inviting the collaboration of consumer groups[†]
14 Type B: Research programmes consulting consumer groups
 5 Type C: Research programmes inviting the collaboration of individual consumers
13 Type D: Research programmes consulting individual consumers
12 Type E: Research programmes responding to consumer action with collaboration
 2 Type F: Research programmes responding to consumer action with consultation
 7 Type G: Research programmes tapping consumer perspectives indirectly
 7 Type H: Consumer-led research programmes

*12 of these reports contained accounts of both purposeful **and** opportunistic involvement of consumers.
[†] Numbers in this box relate to the number of episodes; elsewhere, numbers relate to the number of reports.

FIGURE 2 *Identifying reports of consumer involvement in setting research agendas*

than detailed descriptive reports drawing on reflective discussion of participants. For this reason, we have not distinguished reports according to their strength of evidence, and the findings of this review must depend upon pooled opinions.

Type A: inviting consumer group involvement through collaboration

Where research programmes invited consumer groups to collaborate, we designated it as Type A engagement (*Figure 3*). Collaboration involved ongoing, developing working relationships.

We found that the typical forum for Type A approaches was the research committee. Consumer groups have been invited to participate in setting research agendas through various forms of committee membership. Our definition of committee membership incorporates consumer membership on advisory groups, panels and committees of research programmes. One example was consumer committee membership of NHS research programmes such as prioritising panels for the NHS HTA programme.

An alternative forum was the research team, which covered interactions where consumers worked as

equal partners with researchers. Teamworking was a less formal process than research committee membership and sometimes included researchers working with members of communities.

Collaborations with consumers within the Cochrane Collaboration were international and appeared to be less formal or more flexible than committee membership. An independent review of consumer agendas combined recommendations for consumer involvement with both committee membership and more flexible team working.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type A approaches to consumer involvement.

A.1 Committee membership
Committee membership has been a common method for seeking consumer perspectives for the priority setting exercises during the first decade of the NHS R&D programme. Most examples that we found combined collaboration with a few consumers with a broader consultation, and these are described in Section A.4. We found two other examples of committee membership. One of these was too new for details to be available and the other was a series of 'working groups' about the research needs of vulnerable people.

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A: Committee membership, teamworking, international collaboration,		
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

FIGURE 3 *Framework for describing Type A consumer involvement in research agenda setting: inviting consumer group involvement through collaboration*

- The Health Education Authority (HEA) convened a series of agenda setting working groups in 1996 which addressed the research needs of vulnerable groups: older people, low-income groups, people who are homeless, refugees, people with mental health problems, lone parents and children and young people. The HEA published the findings in a series of monographs. We considered in detail the group addressing the needs of homeless people. The group of 11 included clinicians, sociologists, public health consultants, specialists in housing, health promotion, mental health and sexually transmitted diseases and two members from organisations representing homeless people. The group pooled their expertise and prepared a report that was based on a 2-day workshop.[24] They recommended a research agenda of mapping exercises, process evaluations and action research. How and what the consumer members of the group contributed are unclear. Further details are reported in Chapter 5.

- The recently convened UK National Programme on New and Emerging Applications for Technology (NEAT) is managed through an Advisory Group composed of 'representatives from a range of stakeholders' including one member from a national patient interest group.[25] Further information was not available at the time of writing.

Reviewers' commentary
Neither of these programmes offered any reflection on the methods they employed for agenda setting or for consumer involvement, although the NEAT programme is ongoing and may do so in future. Little could be learnt about consumer involvement in the absence of detailed reporting or critical reflection. The NEAT programme had only one consumer member. This may be considered insufficient for effective participation and may attract concerns about 'tokenism'.

A.2 Team working
More flexible team working was a feature of some collaborations that had been convened to conduct research or review services.

- The Center for Health Policy and Programme Evaluation at the University of Wisconsin's Medical School led a collaborative research project between 1994 and 1996 and published their work in 1997.[26] The Center actively engaged grass-roots organisations, service users and volunteers from five diverse groups in a

two-stage evaluation strategy of a community partnership programme funded by the American Federal Center for Substance Abuse Prevention. In stage 1 they involved community groups in the design of instruments for evaluating grass roots organisations. In stage 2 the grass-roots organisation members selected topics they wanted to explore in detail. These ranged from evaluation of single events to researching the long-term effects of collective social activism. The groups were then trained in research methods and given ongoing support to conduct their chosen projects.

Reviewers' commentary
In this episode, the broad topic of evaluating grass-roots organisations was set by the research programme. Subsequently the academics claimed to have elicited a consumer agenda by investing in training, resourcing and developing a working relationship with community groups. The opportunity for consumers to conduct the research they called for may have been a factor in their choice of topics.

A.3 International collaborations
The Cochrane Collaboration is an international organisation with the mission of preparing, maintaining and promoting the accessibility of systematic reviews of the effects of healthcare policy and practice.[27] Its principles include "minimising bias through … ensuring broad participation; striving for relevance by promoting the assessment of interventions using outcomes that matter to people; [and] enabling wide participation … by reducing barriers to contributing and by encouraging diversity". These principles encapsulate consumer involvement and we found several reports of consumer involvement in the Cochrane Collaboration. Cochrane Review Groups are collaborations between consumers and professionals which are often less formal than committee membership,[28–31] perhaps necessarily in view of their international nature. Teamworking may be a more appropriate descriptor.

- The College of Health, a national charity set up to represent the interests of patients and promote greater user involvement in health and social care, surveyed Cochrane Review Groups in 1998 to find out the extent to which the Cochrane Collaboration involved consumers as members of Cochrane Review Groups, and to explore the emphasis that Review Groups placed on identifying and collecting information on outcomes identified by patients as being important indicators of quality and

effectiveness of treatment and care (patient-defined outcomes).[31] The emphasis on 'patient-defined' outcomes rather than 'patient-centred' outcomes invoked consumer involvement in setting research agendas. The survey found that four Review Groups had made some headway involving consumers through a variety of mechanisms. Of these, the Consumer and Communication Group had a consumer as their coordinating editor in a team of four editors and a list of consumer-defined outcomes incorporated into the formal description of its scope of work. It also required reviewers to identify how they were going to assess patient defined outcomes as part of their methodology.

- The Cochrane Musculoskeletal Review Group reported their working methods at the Cochrane Colloquium in 1999.[29] They found consumers by following the advice of contacts including the Canadian Cochrane Centre, the Cochrane Consumer Network and the Arthritis Society and by hearing consumers speak at meetings. The roles for these consumers were defined through a process of consultation and consensus development. These roles included working "in the community to seek consultation on various topics in the area of musculoskeletal disorders which members of [the Arthritis Society] feel are important topics to have systematically reviewed". The group had identified different ways for making consumer involvement successful. These were related to communication, support, facilitated discussions, formal terms of reference, feedback and recognition of achievements. With such a supportive framework, consumers have contributed in various ways. These included giving advice on consumer needs (for instance, evidence comparing different drugs, rather than evidence comparing drugs with placebos alone), and assistance in developing partnerships with other like-minded organisations. The Review Group concluded that "the enthusiasm and involvement of the consumer groups has led to new consumer-driven initiatives and having consumers as partners in the review group process results in more research truly relevant to consumer and health workers' concerns".

- Four Cochrane Review Groups (for breast cancer, HIV/AIDS, Consumers and Communication and Musculoskeletal problems) collaborated to review their efforts for involving consumers in setting priorities and presented

their findings at the Cochrane Colloquium in 1999.[28] They concluded that "consumer involvement in priority setting within review groups is achievable and has numerous benefits including the production of systematic reviews addressing questions (and using outcomes) of relevance and meaning to consumers". All four groups had at least one consumer editor. In the breast cancer group two consumer editors represented and reported to their relevant constituencies. In the HIV/AIDS group, the consumer editor participated in priority setting, liaised with consumer groups, offered a perspective from the developing world and was responsible for consumer synopses of systematic reviews. Consumers also provided a wide range of perspectives as members of advisory boards. In addition, the Breast Cancer Group convened a working party to determine priorities within specific areas. For instance, the consumer member of the Advanced Breast Cancer Working Party brought a unique perspective, held the same responsibilities as other members and was a named co-investigator on a grant application. In addition, some consumers were themselves undertaking reviews addressing questions generated by consumers.

- The Diabetes Review Group also included members of a consumer organisation.[30] The Insulin Dependent Diabetes Trust (IDDT) proposed some topics for review that were not taken forward. We were unable to find any record of terms of reference or methods for involvement. Further details are reported in Chapter 5.

Reviewers' commentary

Broad representation and ongoing involvement were outlined as advantages for consumer involvement in Cochrane Review Groups, with consumers representing multiple constituencies and nationalities.[28] Outcomes of such ongoing relationships were highlighted by a review of ways in which consumers were involved in Cochrane Review Groups, with consumers consulting their constituencies and developing their own roles and responsibilities.[29] The underpinning philosophy of collaboration did not always translate in practice into partnerships of equals. Lack of a consistent strategy for involving consumers in review groups[28,31] could be seen as a disadvantage. This may explain why some groups lagged behind in identifying patient-defined outcomes[31] and why some faced difficulties involving consumers at all.[30,31]

A.4 Combining collaboration with consultation

Some agenda-setting exercises combined collaboration and consultation with consumer groups.[32–37]

- The NHS embarked on a period of reorganisation with the establishment of its research and development strategy in 1991. The Advisory Panel on Methods to Promote the Implementation of Research Findings in the NHS, established in 1994, was the eighth panel to set priorities for the NHS R&D programme[33] and completed its review in 6 months. The group was multidisciplinary and included purchasers, providers, researchers, policy makers and a consumer. The group was informed by wide consultation within the NHS and a supplementary consultation of targeted key individuals in other sectors, and by expert papers. Four workshops were convened to focus on the role of consumers, the media, changing clinical practice and policy and financial levers. The consumer member of the panel was resourced to convene the consumer workshop. The workshop "engaged a wide range of consumers to discuss consumers as levers for change in others (for instance, as a lobbying force) and as users of research findings themselves. … Examples of issues raised at this workshop included how to involve users in developing practice guidelines, the use of patient care plans for users to monitor treatment and evaluating the effects of different formats of information for patient use". The workshop was reported in full by the consumer panel member[37] and a summary appeared in the published report by the research managers.[33] The consumer report[37] described how the participating consumers were new to researching the implementation of findings but were ready to build on their experience of working in partnership with researchers and health professionals in clinical trials. Stumbling blocks included the need to explain to consumers the exact questions they were being asked to address and the technical and organisational background of the exercise. This was partly overcome with the use of visual aids and practical examples.

- A parallel NHS R&D programme was established in 1994 for Mother and Child Health.[38–40] The group approached national organisations and individuals, representing consumer interests in a written consultation and through regional workshops. A series of small focus groups and surveys were also carried out to engage ordinary users of the service in informal discussion on problems and opportunities for research in child health. The aim of this work was to provide a 'dipstick' of consumer views in settings such as general practice, health centres, residential children's home, playgroups and nursery schools, secondary school and child development centres. The report of this work was made available to three panels on child and adolescent health convened to prioritise research. One of these panels included one member from a consumer group. Other sources of consumer views made available to the panel on mother and infant health included a National Childbirth Trust survey of its local branches on problems and opportunities for research[41] and a national Delphi study conducted by the National Perinatal Epidemiology Unit.[42,43] The NHS report did not include a record of the research topics identified or prioritised by consumers. The formal reflections on the process did not address consumer involvement. However, in considering research in the area of mother and child health, the group recognised the importance of patient-centred services and recommended that "those taking forward research in the priority areas seek actively the views of consumers". Further details are reported in Chapter 5.

- The Department of Health 'Health in Partnership' initiative lived up to its name by involving consumers through a variety of methods throughout the process, from identifying topics to commissioning the research. In 1999, the Department of Health took into account the experience of Consumers in NHS Research Standing Group, and involved lay representatives in all stages of commissioning the programme. Decisions about research topics were informed by a literature review and made in consultation with researchers, practitioners and patient and carer organisations via individual discussions and a large consultation meeting. A commissioning group was established with representatives from each of these constituencies. This group decided to focus on lay involvement in shared decision-making in relation to three areas: individual treatment and carers, service development and the implications for staff training and development. This agenda setting process was reported in no further detail at the 'Research: who's learning?' conference in

2000.[34] The programme continued by commissioning research that actively involved consumers in each project.

- The NHS HTA programme aimed "to ensure that high quality research information on the costs, effectiveness and broader impact of health technologies was produced in the most efficient way for those who use, manage and provide care in the NHS". People from all these groups were involved in determining priorities for the programme. Widespread consultation identified up to 1500 suggestions each year. These were prioritised by expert panels, aided by short scientific summaries of possible research areas (vignettes) written by in-house National Coordinating Centre for Health Technology Assessment (NCCHTA) staff with the help of experts in the field. Researchers were then commissioned, following peer review, to produce health technology assessments, which are published – again after full peer review – in the HTA monograph series. Consumers were formally introduced in 1997 and have since been engaged throughout the process.[32] A feasibility study piloted consumer membership of prioritisation panels and consultation of consumers for identifying and refining research topics.

Some consumers have taken questions about their care to telephone helplines. The NHS HTA programme explored the feasibility of translating records of consumers' questions into research questions. Unfortunately, records for service monitoring were not sufficiently detailed for the task, and lack of direct communication precluded discussion to elucidate the relevant research issues.[32]

When seeking research topics, face-to-face discussion with a consumer group was more productive than scanning consumer research reports or contacting consumer health information services. Consumers were willing and able to play active roles as panel members in refining and prioritising topics and in commenting on research plans and reports.

When refining research topics, a representative of a condition-specific consumer group was consulted for the preparation of each of three vignettes. Consumers tended to highlight issues about patients' views, social contexts, information and support needs and long-term outcomes. These issues were usually not addressed by professionals, who tended to focus more on technical and economic aspects of the work. Thus consumers provided important background information for panel discussions about priorities for research.

The feasibility report identified ongoing relationships as an advantage for effective consumer participation. Support such as induction, training and mentoring was also considered essential, as was avoiding 'tokenism' by having two consumer members of each panel. Disadvantages in terms of 'process' barriers to consumer involvement on committees were outlined in the HTA pilot study in terms of attitudes of professionals, time pressures and language barriers.[32] The authors recognised within the HTA programme elements of a learning organisation: learning from each other, from experience and from outsiders and willing to accept and adapt to new ideas and changes through a shared vision[44] (see also Section B.2; further details are reported in Chapter 5.)

- The priority-setting phase of the national NHS programme of commissioned research for primary dental care spread over a period of 11 months from 1993 to 1994.[45] Like the other time-limited NHS R&D programmes, the programme was directed by an advisory group. The 260 areas identified were first condensed into 26 broad topic areas and justification papers were prepared for each topic area by independent reviewers, who had been identified by the advisory group. These broad areas were then prioritised by the advisory group, with a final 20 priorities being identified, of which the top 10 were noted as the highest priority. This programme differed from other national programmes in that it was required to pay particular attention to methods of incorporating a consumer viewpoint at the development and evaluation stages of their work.

In addition to taking their concerns to consumer health information lines, consumers may approach their MPs. The NHS R&D programme for primary dental care turned to both of these sources for records of consumers' queries. From these they found that consumers were concerned about access and availability of services, school dental services, water fluoridation and cross-infection control in general practice.
Other input included a consumer member of the panel, a written consultation of consumer groups and charities, a review of evidence submitted by the Association of Community

Health Councils for England and Wales and a review of questions raised in Parliament. The report also differed from reports of other advisory groups in that it was required to reflect on the process of consumer involvement and recorded consumer concerns. The general broad themes of concern were consistently identified through different routes: written consultations to consumer groups, reviewing parliamentary questions and questions to telephone helplines, and consumer membership of the prioritising panel. These could be matched against the research areas subsequently prioritised, but no information about research commissioned was available from the website in June 2001. (Further details are reported in Chapter 5.)

- Over a 12-month period from 1999, the Northern and Yorkshire NHS Regional R&D Directorate used a combination of methods to determine priorities for research. They started with questionnaires and focus groups that identified older people as a priority area. This was followed by two workshops to identify and prioritise research questions within this area.[36] A range of consumers was involved in each of these stages. The programme worked with local individual consumers and representatives of consumer groups with little previous experience of research. Five research topics were identified. These were subsumed into three broader research areas in the commissioning brief. The commissioning brief also asked researchers for "recognition of the user perspective within applications". (Further details are reported in Chapter 5.)

Reviewers' commentary

All these programmes were able to draw on direct prior experience of involving consumers in research. Combining collaboration and consultation seemed to be an effective way of involving consumers. More was learnt from the reports that both distinguished clearly the contributions of the consumers from the overall output of the programme agenda; and reflected on the methods of involvement.

Key messages

When research programmes invited consumer groups to collaborate:

- Committee membership and international teamworking provided a structure for consumers to consult their peers and input a broader range of consumer views into the process and for responding to criticism from advocacy groups. Indeed, topics for research were identified and recorded by consumers when they were empowered to lead wider consultations.[29,33,37]

- Consumers needed to be informed about the technical and organisational background of the work in which they are involved. This has been helped with the use of visual aids and discussion of practical examples.[32,37]

- Consumer involvement methods were developed further when consumers were involved as partners in reflecting on working practices.[28,29,32]

- More was learnt about consumer priorities and methods for identifying them when programmes were required to reflect on the methods for incorporating consumer perspectives.[45]

- Consumer perspectives were reported with greater confidence when a range of methods had given consistent views.[45]

- Consumer membership of committees needed facilitated democratic processes, openness, appropriate recruitment, support and training.[32]

- Collaborations needed to confront tensions and benefit from careful management to avoid divisions or breakdowns in communication between consumer members and professionals.[32]

- Collaborations convened to set research agendas may continue by conducting collaborative research.[34]

- Collaboration was similarly successful when consumers were empowered as partners, and reflection on working practices led to further developments.[28,29]

- Broader consumer representation was possible through advocates as members of teams.[28]

Details of Type A approaches are given in *Table 1*.

TABLE I *Type A Inviting consumer group involvement through collaborations*

Author(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
A.1 Committee membership							
Power et al., *1999[24]* *Case investigated in more depth for UK episodes (see Chapter 5)*	*HEA*	*Health Action for Homeless People*	*Two working group meetings*		*Experience of collaboration led to research project*	*Only one consumer on advisory group. No reflection on consumer involvement and no lessons learned*	*Description by participant researcher/ manager, interviews with researcher/ manager and consumer*
NHS Executive, 2000[25]	New and Emerging Technologies		Committee membership			Only one consumer on advisory group. No reflection on consumer involvement and no lessons learned	Description by participant researchers/ managers
A.2 Teamworking							
Lackey *et al.*, 1997[26]	Centre for Health Policy and Programme Evaluation, University of Wisconsin Medical School	Activists from grassroots organisations, service users, volunteers	Teamworking: training and support for conducting research	Empowerment	Consumer and academic criteria for evaluating empowerment	Broad involvement from diverse community groups	Description by participant researchers/ managers
A.3 International collaboration							
Kelson, 1999[31]	Cochrane Review Groups	Consumer groups	International collaboration	Partnership	Consumers identifying patient-defined outcomes for some groups	Lack of consistency. Lack of overall strategy	Independent survey by consumer researcher
Kelly, 1998[29]	Cochrane Musculoskeletal Review Group	National consumer groups	International collaboration	Partnership	Consumer suggestions for research and ways of collaborating	Consumers defining own roles/responsibilities within collaboration and taking consultation to own constituencies	Description by participant researchers/ managers

continued

TABLE I *Type A Inviting consumer group involvement through collaborations (cont'd)*

Author(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Ghersi *et al.*, 1999[28]	Four Cochrane Review Groups: Musculoskeletal; Breast Cancer; HIV/AIDS; Consumers and Communication	National review groups	International collaboration	Partnership		Broad representation. Lack of coordination of methods for involvement. Range of consumer groups developing methods in relative isolation	Description by participant researchers/ managers
Hirst, 1997[30] *Case investigated in more depth for UK episodes (see Chapter 5)*	Cochrane Diabetes Review Group	National review group: IDDT	International collaboration	Partnership		Researchers did not address consumers' priorities	Description by participant consumer
A.4 Combining collaboration and consultation							
Oliver, 1995;[32] NHS Management Executive 1995[29]	NHS R&D implementation of research findings	Individual consumers and representatives of consumer and community groups	Committee membership + consumer-led workshop	Organisational change	Consumers identified: promising methods for involvement; topics for research; reflections on agenda-setting process	Consumer committee member led wider consumer consultation with programme resources	Description by participant researchers/ managers. Description by participant consumer

TABLE 1 *Type A Inviting consumer group involvement through collaborations (cont'd)*

Author(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
CRDC Advisory Group on Mother and Child Health 1994;[38] Trent Regional Health Authority 1994;[40] NHS R&D Directorate 1994[39]	NHS R&D Mother and Child Health	Consumer groups and individual service users	Committee membership, focus group, surveys		Research agenda without specifying consumer contributions	Broad involvement with multiple methods	Description by participant researchers/ managers
Hills and Farrell, 2000[34]	Department of Health Health in Partnership	Patient and carer groups	Individual discussions, large consultation meeting	Partnership	Research agenda focus on lay involvement in 3 areas: individual treatment and carers, service development, lay involvement in staff training		Description by participant researchers/ managers
Oliver, 1998[32] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS HTA*	*National consumer groups; journalist*	*Committee membership*	*Organisational change; learning organisation*	*Three consumer topics identified; research priorities published without detailing consumer contributions*	*Continued collaboration in light of perceived success. Recognition of barriers to consumer involvement. Training and mentoring schemes in place. Attitudes of professionals, time pressures and language presented barriers*	*Description by participant researchers/ managers*

continued

TABLE 1 *Type A Inviting consumer group involvement through collaborations (cont'd)*

Author(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Breckenridge, 1994[45] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D Primary Dental Care*	*Members of public, consumer groups*	*Trawling helpline records, and questions asked in Parliament; committee membership; written consultation*		*Identified areas of concern to consumers*	*Indirect methods applicable where consumer population hard to define*	Description by researcher/ manager and interviews with researcher/ manager
Doble, 1999[36] Northern and Yorkshire Regional Research And Development Programme 1999[118–121] *Case investigated in more depth for UK episodes (see Chapter 5)*	*Northern and Yorkshire Older People*	*Older people's groups*	*Written consultation, focus group*		*Five topics prioritised, without specifying contributions of consumers. Grant applications asked for 'recognition of the user perspective'*	*Drew on personal experience of voluntary sector*	Description by participant researchers/ managers

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A		
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

Type B: Written, face-to-face, multiple face-to-face, written + face-to-face consultations

FIGURE 4 *Framework for describing Type B consumer involvement in research agenda setting: inviting consumer group involvement through consultation*

Type B: inviting involvement of consumer groups through consultation

Where research programmes consulted consumer groups, we designated it as Type B engagement (*Figure 4*). We found that consumer groups have been invited by a variety of research programmes to participate in setting research agendas through written consultations and through face-to-face discussions or a combination of the two.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type B approaches to consumer involvement.

B.1 Written consultations

In the UK, consumers have been involved in broad written consultations conducted by research programmes,[46,47] a research unit[48] and a professional body.[49]

- An NHS Advisory Group was established in 1993 to set R&D priorities for cancer.[47] The Group had 15 members with expertise in organisation, management and delivery of

cancer services and research. Research topics were identified from a widespread consultation, NHS reports and five workshops. The consultation included 16 patient interest groups. Seven of these responded. Included in the terms of reference of this group was the responsibility "to evaluate the approach taken by the group to setting priorities, and to provide a paper on this approach to the Central R&D Committee". There was no mention of consumer involvement in the reflection on the methods for agenda setting, nor were consumers' priorities recorded.

- A similar exercise by a parallel Advisory Group for cardiovascular disease and stroke research,[46] with similar terms of reference, received responses from 12 of 31 consumer groups. Again, this group did not record consumers' priorities or lessons learnt from the experience of involving them in agenda setting.

- The Chartered Society for Physiotherapy consulted its members and external audiences to establish its 1997 priorities for physiotherapy research.[49] A Delphi study attracted a broad cross-section of respondents including physiotherapists, consumers and medical research charities, Directors of Public Health, other professional bodies, general practitioners,

Directors of R&D programmes and the Department of Health. Too few people were interested in a subsequent consensus conference to continue with this plan. The responses of consumer groups and medical research charities were combined in the report of this exercise. Twelve of 91 consumer groups and medical research charities responded, suggesting 20 (10%) of the topics. Nine of these 20 topics appeared in the Delphi study's final list of 24. All nine were also suggested by other groups. The results were used to submit priorities to the NHS R&D HTA programme's call for suggestions in 1997. This exercise was reviewed later by independent researchers, who concluded that the advantages of involving consumers in a Delphi survey were that (a) consumers may well identify priorities that professionals at first neglect and (b) the exchange of views may lead to increased consensus, but not necessarily.[35]

- In 1993, the Department of Health funded the National Perinatal Epidemiology Unit to conduct a three-round Delphi survey to identify priorities for research as perceived by a random, stratified sample of midwives.[48] The first questionnaire aimed to elicit important practice-relevant topics for research. The second questionnaire listed these topics after they had been sorted and categorised and respondents were asked to rank the topics in order of their perceived importance. The third round enabled respondents to refine their priorities further. The result of this study[43] informed the NHS R&D Mother and Child Health agenda-setting exercise. A second complementary survey explored the views of representatives of the major UK maternity organisations,[48] but the findings were not published.

Reviewers' commentary
These written consultations were all reported from the perspective of professional research. They targeted a broad range of people but low response rates and self-selection may have influenced the priorities. These low response rates could be attributed to the short timetable, lack of guidance or support for (or dialogue with) the consumers and consultation overload or failure to engage consumers who are faced with competing interests, such as campaigning or peer support. An independent review of written consultations[35] confirmed the lack of dialogue in this method and concluded that this led to mismatches between priorities of consumers and professionals.

When research programmes have taken the lead in setting the research agenda, even when reflecting on their methods, some have overlooked the efforts and consequences of trying to involve consumers.[46,47] In this way, opportunities to learn about consumer involvement have been lost.

The output of an agenda-setting exercise can be assessed in terms of the agenda or the subsequently commissioned research. The Chartered Society of Physiotherapy listed its 20 top priorities for 1997 and submitted them to the NHS HTA programme. The HTA programme prioritised five of these and commissioned three research projects. However, all five of these topics had previously been identified by the programme, between 1993 and 1996. This highlights the need for good information systems to support agenda-setting exercises across organisations.

B.2 Single face-to-face consultations

We found face-to-face interactions between consumers and research programmes that have included focus groups,[32] interviews,[50] and seminars.[51] For each episode, either single face-to-face events were supplemented by other information or communication before or afterwards[32,37,51] or more than one face-to-face consultation was involved.[52–55] All of these were reported from the perspective of the research programme.

- The NHS HTA programme was introduced in Section Type A and further details are reported in Chapter 5. Here we report the consultation aspect of this work. In 1997, the NHS HTA programme piloted new methods for involving consumers in identifying research topics. Efforts to elicit consumer suggestions for health technology assessment included a meeting between staff of the NHS HTA programme and a consumer group.[32] The consumer group had experience of conducting its own research and its staff all had personal experience of mental ill health. The consumers hosted the meeting and were sent background information and a request to think about possible research topics in advance. Discussion focused on research that is relevant to health service users and developing skills for framing research questions in order to evaluate the effects of care. The research programme reported that the consumers found framing their concerns to fit the scope of the HTA to be an easy exercise but other commitments prevented them from finding the time to submit their ideas via the HTA website. The research questions identified were:

1. How effective are primary care interventions for parents of children with mental health problems?
2. Can acupuncture relieve symptoms of schizophrenia, manic depression or acute severe depression?
3. What impact does addressing religious and spiritual needs have on mental health?

This was more productive than indirect methods of scanning consumer literature or questions posed to consumer helplines.

- In 1994, the Royal College of Nursing's research unit invited user groups with experience of the research process (MIND, Cruse Bereavement Care, The Spastics Society, the National Consumer Council, the National Childbirth Trust and The Patients' Association) to a seminar with the aim of discussing how users might become more involved in the research for health and in the Royal College of Nursing's own research.[51] The seminar participants identified key issues and methods for user involvement in research for health and agreed that consumers wish to be involved in "setting research agendas in partnership with professionals and sponsoring bodies with equal weight given to all views".

- One of the UK national programmes for commissioning research addressed the challenge of getting research findings into practice. This work was introduced in Section Type A, combining collaboration with consultation. Here we focus on the consultation. The Advisory Group for Methods to Promote the Implementation of Research Findings in the NHS was convened in 1994 and had 6 months to report its work.[33] It included two consumer organisations and an umbrella group in the written consultation for research topics, and received only one response from a consumer perspective. More fruitful was convening a working group on the involvement of consumers in the implementation process.[37] "The working group … engaged a wide range of users to discuss consumers as a lever for change in others (for instance, as a lobbying force) and as users of research findings themselves. Consumers included members of the public, individual patients or carers, organised user groups and statutory bodies such as Community Health Councils. Examples of issues raised at this workshop included how to involve users in developing practice guidelines, the use of patient care plans for users to monitor treatment and evaluating the effect of different formats of

information for patient use."[33] The subsequent agenda included "exploring and evaluating roles for health service users in research implementation".[33] The Advisory Group reflected on their task of delivering a research agenda within 6 months while balancing the need for scientific rigour and a pragmatic acceptance of working within a tight timescale. "Given these constraints the Advisory Group found the four working groups particularly helpful. These enabled informal discussion in some depth in particular areas, including the involvement of consumers … ." In less formal correspondence, a consumer participant reflecting on this process saw particular value in the style of the consumer-led workshop where

> "the level of debate was significantly more passionate (for want of a better description) than is the case in most meetings of this kind … I think this is a tribute to the freedom allowed by the [consumer] Chair and the level of psychological 'safety' that participants felt within the workshop. This freed people to speak their mind (both a risk and a benefit in some instances) and to participate more fully in discussions.

> "I personally feel that this sort of subjective element will be crucial if consumers are to be full participants in any aspect of R&D programmes. People must be able to feel free to express their feelings about the issues under consideration, and not simply give a dispassionate reasoned response – that is more often the job of professionals such as clinicians and academics! Consumer representation often fulfils the function of a sort of unknown 'X-factor' … a catalyst for new ideas, new ways of looking at something that those of us who are more formally involved in research and implementation often forget."[56]

- The number of Americans over 65 years of age with psychiatric disorders was predicted to increase from 4 million in 1970 to 15 million in 2030. Current services for geriatric mental disorders were considered poor. Against this backdrop, a workshop was convened to develop a consensus statement to influence the national research agenda for mental disorders.[57] It involved professionals from different disciplines and institutions and members of advocacy groups. The resulting research agenda addressed "prevention, translation of findings from bench to bedside, large-scale intervention trials with meaningful outcome measures, and health services research". However, there was no record of consumers' contributions nor reflection on the process of consumer involvement.

Reviewers' commentary

Face-to-face events supplemented by other information or communication had the advantages of informed debate. This was recognised as such both in reports written from the research programme perspective[32] and in reports written from the consumer perspective,[37] and can be attributed in each case to the circulation of background information in advance. Consumers reported the debate as fully involving participants and attributed this to the choice of facilitator, a fellow consumer.[37] The informality and 'psychological safety' within a workshop were held to be important in defining its success.[56] On all these occasions, consumers identified topics for research.[32,37,58] The advantages of partnerships and building alliances between consumers and professionals were emphasised in two of these reports.[56,58] These advantages were attributed to enabling effective participation by developing relationships and understanding over time.

Identification of research topics by consumers did not necessarily lead to prioritisation and commissioned research. Ultimately, no research was commissioned by the HTA for any of the three questions identified by consumers.[32] A search of the UK National Research Register 2001 issue 2 revealed both completed and ongoing observational studies addressing topics 1 and 3, but no studies addressing impact of intervention and no studies addressing topic 2.

Consumers' ideas presented to the Advisory Group on the Implementation of Research Findings[37] encompassed the involvement of consumers in their individual care and in the development and evaluation of services. These were incorporated into a broad topic of "Exploring and evaluating roles for health service users in research implementation".[33] Of the 35 research projects subsequently commissioned, eight were explicitly about consumer involvement, but all of these considered consumers in their role of individual patients rather than active participants in planning and evaluating services. See http://www.doh.gov.ntrd/rd/implem/commiss/complist.htm, searched 6 June 2001.

B.3 Multiple face-to-face consultations

Two or more face-to-face consultations were convened to address a workplace safety research programme in the USA,[54] and an inner city health research programme in the UK,[52,53] a UK national disability research programme[55] and, in Australia, gene therapy for cystic fibrosis.[50]

- In the USA, the National Institute for Occupational Safety and Health (NIOSH) published its research agenda in 1996. This had been prepared by NIOSH and its public and private partners using a consensus building process in response to a broadly perceived need to address systematically those topics most pressing and most likely to yield gains to workers and to the nation.[54] Because of the research agenda's national scope, the process focused on achieving openness and inclusiveness via the broadest possible public participation. Final research priorities were based on input from working groups (including one of stakeholders), written comments, oral comments made at public and town meetings and other comments made during the deliberations. Three liaison committees (corporate, worker and broader-based stakeholder outreach) increased the range of input into the agenda by securing the involvement of employers, employees, health officials, health professionals, scientists and public health, advocacy, scientific, industry and labour organisations. Town meetings in Boston, Chicago and Seattle captured input directly from health professionals, researchers, organised labour, workers, consumers, businesses, state and local health officials, elected officials and the public at large. A draft agenda was widely distributed for comment before the final all-partners meeting of liaison and advisory group members, agency representatives, working group members and interested individuals. The top priorities of the five working groups and the final agenda were published in the *American Journal of Public Health*, but without any reflection specifically about consumer involvement.

- The NHS Physical and Complex Disability programme was a national commissioned programme that set research priorities over a period of 7 months from November 1992.[55] Like all the other 'time-limited' NHS programmes, it was directed by an advisory group. To identify topic areas for the programme, consumer groups, along with other organisations nation-wide, were targeted by a written consultation. Regional workshops were held to gauge the regional concerns and needs of users and carers. The programme's advisory group had a consumer member. In addition to helping direct the programme, the advisory group members identified and prioritised the research areas identified through the written

consultation and workshops. The 11 broad research priorities included 'consumer views' and 'using carers' views to develop and evaluate new forms of support', and these were well represented in the subsequently commissioned research. Three commissioned projects gave consumers a role in service planning and evaluation: practice guidelines for primary health care teams to meet the needs of Asian carers' needs, evaluating service support to families with a child with sickle cell disorders or thalassaemia and carers' perspectives on discharge procedures for young adults with physical and complex disabilities. (See http://www.doh.gov.uk/research/swro/rd/national/pcd/funded/fulllist.htm. Further details are reported in Chapter 5.)

- In 1996, a UK consultation exercise aimed to gather consumer views on priorities for research and development within the NHS urban areas of North Thames.[52,53] The College of Health, a national charity set up to represent the interests of patients and promote greater user involvement in health and social care, was commissioned to undertake a study involving focus group interviews with 10 established inner London groups, chosen to give insight into a range of experience and views. Ten groups were formed with lay participants and two groups were formed with workers from London-wide voluntary organisations with an interest in health issues. The focus groups with lay participants were convened by working through existing social and community groups. This approach was chosen to achieve the consultation within the project's timetable. It meant that focus group participants knew one another before the meeting, which may have made it easier for them to engage in discussion freely. Organisations were selected from lists of voluntary agencies to represent broad sections of the community (Indian people, young people, older Caribbean people, Bangladeshi women, older white women, tenants' associations, Chinese people, employees, unemployed young people and Somali people). Groups with a particular interest in specific health services or conditions were excluded. Organisations that agreed were given responsibility for convening and hosting a group of up to 12 people. Various difficulties were encountered in setting up the groups. These included:
  1. People who had promised to attend the group not turning up – perhaps because they had received no incentive themselves.

2. People not having a clear understanding of the subject area and its importance, although a project information sheet was sent to all organisations in advance and further explanation was given at the start of each focus group meeting.
3. People not committing themselves for the complete time period of the group.
4. People finding the concepts of research and development difficult to grasp, especially those for whom English was a second language.
5. Problems in translating the concepts into other languages as diverse as Somali and Gujerati, Cantonese and Bengali.
6. Ascertaining in advance the groups' need for interpreting, and ensuring that the interpreter had appropriate skills to assist in facilitating the group.
7. Finding translators competent to translate and transcribe the tape recorded group discussions.
8. Convening meetings within a short time frame.

Both the community groups and the voluntary organisations suggested specific R&D projects. A broad spectrum of priorities emerged: housing, drug misuse, mental health, transport, and the needs of carers. Wider messages from these groups were:
1. Where appropriate, the voluntary sector and the communities themselves would like to be involved in their local R&D programme.
2. No one population group has a bigger priority than others and opinion was divided on priority given to specific issues.
3. Priority should be given to projects likely to make a difference.
4. Improving access to health care for the most disadvantaged groups was a consistent theme.

The consumers' broad priorities and key messages for an inner city health research programme and their concerns were taken forward in the commissioning document but it is unclear what impact they had on the subsequent research. Part of the problem may be that consumers' ideas were broader than the remit of the NHS itself, presenting an organisational challenge to taking their ideas forward.

- A 3-year project on Public Perceptions of Biotechnology at Murdoch University, Western Australia, held a series of communication events with consumer groups, culminating with a workshop in 1997.[50] Although not convened

specifically for the purpose, research priorities were discussed. The development of gene therapies for cystic fibrosis was discussed in qualitative one-to-one interviews and focus groups facilitated by research staff with 16 consumer groups and voluntary organisations such as the Cystic Fibrosis Association of Western Australia, the Birth Issues Group, Tourette Syndrome Association and Buddhists. The aim of the earlier focus group interviews was to explore conversationally the views of a range of 'interested publics' on developments in genetic medicine. The aim of a subsequent gene-technology communication workshop was to continue these conversations by enabling representatives of each focus group to pose some of the questions raised in their group for discussion to a panel of experts in medical genetics, public health and medical ethics. Consumers' questions about setting research priorities included: 'Who will benefit from gene technology, given financial limitations?', 'What does it replace?', and 'Is gene technology motivated by private ownership and profit rather than the betterment of mankind?' Consumers wanted to know whether too much money was spent on gene technology and not enough on possible causes of health problems, such as environmental or nutritional causes.

The authors drew conclusions from the workshop about the nature of consumers' questions and the workshop as a tool for public debate and public policy development. They considered that consumers' questions arose from a comparatively extended process of reflection and emphasised the broader, more contextual, social and ethical ramifications of the new genetics that should be central to continuing debates. They considered that their invitations to 'interested publics' brought to the discussion groups valuable knowledge and experience that helped to contextualise the more technical discussions of medical experts. These groups were seen as potential allies to scientists and educators to the wider public. The authors also valued the process for allowing consumers to raise issues for discussion rather than only responding to a pre-set agenda.

Reviewers' commentary
Multiple face-to-face consultations on a national or regional scale enabled a variety of consumer groups to be involved in research programmes. As with the single face-to-face events, this method was considered successful in gauging the views of local people about research.[52,53]

The NHS Physical and Complex Disabilities (PCD) programme appeared to be unusually strongly influenced by consumer perspectives.[55] This may reflect the long history of disability campaigning.[57] In contrast, the impact of involving consumers in the inner city programme was disappointing. It is worth noting that these consumers came in the main from community groups that had not come together in order to campaign on health issues, but were largely passive participants in a consultation exercise.

The workshop convened as a two-way communication event differed in its output from the other consultations.[50] Rather than recording consumer views or priorities, the authors recorded consumers' questions that they needed answers to in order to formulate their views or priorities. This emphasised the value of deliberative consumer involvement.

B.4 Combinations of face-to-face and written consultations
We found two programmes that used a combination of face-to-face and written consultations[59,60] to engage a range of consumers.

- An NHS Advisory Group was convened in March 1993 to identify priorities for research relating to the interface of primary and secondary care.[59] A wide-ranging consultation exercise was undertaken including informal evidence from workshops and a consumer focus group, written evidence from within the NHS and other interested bodies and submissions from the Advisory Group themselves. The consultation included 27 patient interest groups or charities in its written consultation and received 14 responses. The Carers' National Association devoted one of its monthly meetings to discussing issues relating to the interface between primary and secondary care from the perspective of those looking after sick or dependent individuals. They did not identify specific research topics but discussed issues that they perceived as problematic: availability of facilities, discharge arrangements, professional boundaries and communication. Programme staff hoped that the "anecdotal information generated by this group [would] give a flavour of some of the concerns and needs of the individual user (carer and dependent) of the services". Subsequently the agenda included "systematic evaluation of patients' and carers' needs and views of services".

- NHS research priorities for asthma management were set by an advisory group working over 9 months and reporting in April 1995. A doctor represented patients' interests during group discussions. The group drew evidence from a written consultation with the NHS and other interests, an informal workshop, expert papers and members' views and interests. They combined written consultation with consumer groups with face-to-face consultation with patients.[60] The programme report stated a commitment to dialogue with a variety of stakeholders including consumer groups and patients. Consumer groups consulted by post included the National Asthma Campaign and the British Thoracic Society. Patients in Trent were consulted at a 1-day workshop, which was also attended by clinicians, managers and researchers, but it is unclear whether consumer concerns were taken on board in the prioritisation process. The Advisory Group's reflections on the agenda setting process did not address the methods for consumer involvement.

Reviewers' commentary

A combination of face-to-face and written consultations recorded positive outcomes: capturing consumers' ideas for research topics[33,37] and identifying priorities which placed consumers at the focus of the research topic.[33,59]

The commitment to consumer involvement of the Advisory Group for R&D priorities in relation to the interface between primary and secondary care was evident from their investment of effort, their reflections on the process and the priority they gave to "systematic evaluation of patients' and carers' needs and views of services". The report from Asthma Group's management programme was less forthcoming about consumer involvement, even though it used similar methods and was set in the same organisational context.[60]

We found several exercises, including these two episodes, within the NHS R&D programme where consultation exercises, and reflection on their methods, were integral to the organisational change programme for setting research agendas.[32,37,46,47,55,59,60] Of these, only those that also adapted their methods for involving consumers, thereby managing a diversity of input, also recorded consumer priorities or lessons specifically about methods for consumer involvement.[32,37,59]

Key messages

When research programmes consulted consumer groups:

- More was learnt from interactions where consumers were more directly involved in debate, for instance, through the iteration of a Delphi study,[49] or face-to-face meetings[32,33,36,37,53,55,58,59] or even leading the debate.[37]

- Reflections on the methods for agenda setting sometimes neglected to consider the methods for consumer involvement, and opportunities for learning and sharing were lost.[54,60] In particular, organisational change approaches captured consumers' ideas and priorities[32,33,36,37,49,59] or lessons about consumer involvement[32,33,37,55] only when reflection on the agenda-setting exercise specifically addressed consumer involvement.[47,48] More was learnt from an organisational change framework when the need to reflect on consumer involvement was an advance requirement.[45]

- Working with established community groups was feasible, although it could be time consuming. It provided a route for gauging local opinion from broad sections of the community, including people who were not activists and people who may be unfamiliar with the English language.[36,52,53,59]

- Working with consumers whose shared interests were not health focused faced difficulties with lack of attendance, lack of understanding and lack of commitment.[52,53]

- Least was learnt from simple, written consultations either in terms of consumers' ideas and priorities for research or about the methods used to involve them possibly owing to the low response rates, short timetables and lack of guidance or support for consumers.[47,48]

- The application of community development and health promotion theory[54] attracted broad consumer involvement although did not specify consumers' ideas and priorities.

Details of Type B approaches are given in *Table 2*.

TABLE 2 *Type B Inviting consumer group involvement through consultation*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
B.1 Written consultations							
NHS Management Executive, 1994[47]	NHS R&D Cancer	16 patient interest groups	Written consultation	Organisational change	Research agenda published without detailing consumer contributions	No lessons learned from CI. No reflection on CI	Description by participant researchers/ managers
Advisory Group on Setting Priorities in Cardiovascular Disease and Stroke R&D, undated[46]	NHS Cardiovascular Disease and Stroke	Wide range of consumer organisations	Written consultation	Organisational change	Research agenda published without detailing consumer contributions	No lessons learned from CI. No reflection on CI	Description by participant researchers/ managers
Chartered Society of Physiotherapy, 1998[49]	Chartered Society of Physiotherapy	Recorded on ASLIB	Delphi survey	Organisational change	Consumer-identified research topics (not unique to consumers)	Substantial consumer response. General lack of interest in consensus conference	Description by participant researchers/ managers
Sleep and Clark 1993;[48] Sleep *et al.*, 1995[43]	NPEU: midwifery research	Maternity consumer groups	Written consultation	Reflective professional practice	Research agenda published without detailing consumer contributions	Only reported the Delphi survey of midwives, not the parallel consultation of consumer groups	Description by participant researchers/ managers
B.2 Single face-to-face consultations							
Oliver, 1998[32] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D HTA*	*National consumer group*	*Focused discussion at meeting*	*Organisational change; managing diversity*	*3 research topics from consumer group submitted to the programme – not prioritised*	*Background information sent in advance. Informed discussion with a consumer group. Consumer view – more time would have been useful*	*Description by participant researchers/ managers; interview with consumer*
Poulton, 1994[51]	Royal College of Nursing	National consumer groups	One-day seminar	Organisational change	Consumer-suggested research topics and views on methods of involvement	Targeted invitations. Built on experience of consumer groups' experience of research	Description by participant researchers/ managers

TABLE 2 *Type B Inviting consumer group involvement through consultation (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
NHS Management Executive; 1995;[33] Oliver, 1995[37]	NHS R&D implementation of research findings	Individual consumers and representatives of consumer and community groups	Prior consultation of participants to inform their workshop discussion	Organisational change	Consumer-identified research topics, promising methods for consumer involvement	Background information in advance. Time for thought and discussion. Consumer-led event. Informed and animated debate	Description by participant researchers/ managers. Description by participant consumer
Jeste *et al.*, 1999[57]	Geriatric mental health	Advocacy groups	Consensus conference	Organisational change	Research agenda published without detailing consumers' contributions		Description by participant researchers/ managers

B.3 Multiple face-to-face consultations

Rosenstock *et al.*, 1998[54]	NIOSH	'Stakeholders', e.g. employees	Town meetings	Health promotion, community development	Research agenda published without detailing consumer contributions	Broad participation/ inclusiveness. Variety of meetings involved different publics. Consumers not involved in all stages of process	Description by participant researchers/ managers
NHS R&D undated[55] Case investigated in more depth for UK episodes (see Chapter 5)	*NHS R&D Physical and Complex Disabilities*	*Members of consumer network*	*Regional meetings*	*Organisational change*	*Research agenda published without detailing consumer contributions. Lessons for consumer involvement*	*Reflection on working methods. Recommend more balanced involvement of purchasers, providers, users and researchers in future exercises*	*Description by participant researchers/ managers*
Wiles and Brownfoot, 1997;[52] NHS Executive North Thames, 1996[49]	North Thames Inner City Health	Established community groups and voluntary sector groups	Focus groups		Consumers set criteria for prioritising; 3 broad priorities outlined and key messages for research	Open discussion with community groups. Gauged a 'regional' view. There were unresolved conflicting views. Full reporting of consumer involvement. Consumer concerns were taken forward in commissioning document	Description by consumer involvement facilitators

continued

TABLE 2 *Type B Inviting consumer group involvement through consultation (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Schibeci et al., 1999[50]	Public Perceptions of Biotechnology, Perth, Australia	Consumer groups and voluntary organisations	Interviews, focus group discussion and workshop	Partnership	Consumer concerns about broader contextual, social and ethical issues		Description by participant researchers/ managers
B.4 Combining face-to-face and written consultations							
NHS Management Executive, 1994[59]	NHS R&D interface of primary and secondary care	National carers' group	Written consultation, focus group hosted by carer's group	Organisational change	Agenda item: "systematic evaluation of patients' and carers' needs and views of services"	Aimed for 'flavour of [consumers'] concerns and needs' to be reflected in agenda	Description by participant researchers/ managers
Department of Health, 1995[60]	NHS R&D Asthma	Consumer groups for asthma	Written consultation	Organisational change	Research agenda published without detailing consumer contributions	No lessons about consumer involvement	Description by participant researchers/ managers

CI, consumer involvement.

Type C: inviting involvement of individual consumers through collaboration

Where research programmes invited individual consumers (not consumer groups or representatives of consumer groups) to collaborate, we designated it as Type C engagement (*Figure 5*). We found that individual consumers have been invited to participate in setting research agendas through teamworking.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type C approaches to consumer involvement.

C.1 Teamworking

Our definition of teamworking covers interactions where consumers work in partnership with researchers. Teamworking is a less formal process than committee membership and may include researchers working with members of communities.

- For instance, a research team in California set out to make children not the object of their research, but equal co-investigators.[61] The young people came from different backgrounds, but most were from families with a low income. Funding was allocated for four pilot projects in which teenagers from poor urban neighbourhoods were brought together daily for 6–8 weeks during the 1995 summer vacation. Each project undertook some form of participatory action research. The young people selected an issue or problem in their environment that was important to them, researched it and presented their findings to the community. A small number of adults took part, assisting and guiding as needed, and documenting the process, but not directing. All participants, adults and young people, were paid for their work. One adult at each site acted as monitor, maintaining an ethnographic narrative account of events as they occurred, largely through participant observation. The overarching question of the researchers was, 'how can adults engage young people in community-based public health research and action to improve their environments?' Specific questions included: What is the appropriate role of adults? What help (if any) do adults or children need in this kind of work? What kind

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A	Type B	
	Inviting individual consumers		Type C: teamworking	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

FIGURE 5 Framework for describing Type C consumer involvement in research agenda setting: inviting individual consumer involvement through collaboration

of problems do young people select to work on? What kinds of solutions do they propose? What benefits might be expected from this kind of work?

The authors concluded that teenagers, including those living in very difficult circumstances, can make a strong contribution to research and action on their own behalf, if given the opportunity, respect and support they need. Allowing them to select and frame their own issues seemed to be a crucial element. In this study they chose pollution of a bay where their families fished, a lack of youth recreation places, library closures, alcoholism in the home and local environmental politics. All of these pointed to children's increasing lack of 'safe spaces'. Adults doing this work must be prepared to share decision-making (and funds) with boys *and* girls [authors' emphasis]. In this case success was marked not only in identifying research problems and solutions, but also in the young people's increased self-esteem, social awareness and social responsibility, revealed by their discussion at a 3-month follow-up workshop.

The authors described their initiative as "multicultural, transdisciplinary research … [that] drew on four principle sources, all of which require an ecological and participatory approach: participatory action research, self-directed problem-based learning, environmental education, and community learning". They drew on other literature to define these four theoretical bases. "Participatory action research is an empowering form of communal inquiry … led by a community 'promoter'; it validates local knowledge and is consciously directed towards community action to improve local conditions. It involves elements of research, community organising, planning and advocacy. Practitioners claim that it can, under certain circumstances, help make individuals more aware and equip them to cope with change in their world and that it produces serious and trustworthy knowledge that can open the way for new forms of creative collaboration and alternatives to authoritarian structures and traditional patterns of exploitation."

- Another example of teamworking was an Israeli training programme for older people. In 1990, the Bar-Elan University began to engage older people in social gerontological research.[62] The older people were active participants in a

process of their own design and under their own control, offering a new social role for retired people and empowering older people as creators of new knowledge about ageing. Rigorous efforts were made to clarify with the participants that they were not being trained as research technicians, interviewers, statisticians or experts in research methodology. The emphasis was on: (1) what is important to study and why; (2) the importance of the research question and the relationship between the definition of the research questions and the meaning of the results; and (3) the nature of the interaction effect between researcher and the subjects of the research process. Graduates of the programme were given the opportunity to continue research in a supportive environment. Research projects have been completed, sometimes on difficult and sensitive topics. Some have been published in academic journals or presented at national conferences. This model of educational training programme was relatively cheap to develop and maintain and did not require special facilities or equipment. Such programmes do not require mass participation of large numbers of older people, but the impact of the research generated by such small group efforts can be very significant by legitimising new forms of knowledge about ageing via its dissemination in the news media and through the national 'ageing network'. Specific research topics identified by older people, and researched by them, included: abuse of older people; life contexts of 80-year-olds who are learners in this programme or are learners in non-university settings such as old-age clubs; the effect of pre-retirement training and adjustment to retirement; evaluation of a home-bound learning project; and the impact of knowledge about old age on worry about ageing. In addition to equipping students with new skills, the programme worked to empower third-agers to assume an active role in developing the knowledge base of social gerontology and social policy on ageing.

The programme was also valued for its effect on the participants themselves and their teachers and mentors. "We [the teachers] have undergone a liberating experience in the classroom as the boundaries between older adult students and teacher have broken d own. A moment exists when a person can teach as an expert and simultaneously be a student to his students … The raising of questions is a value-based process where

methodology is perhaps less important than sensitivity".

- A two-way transfer of knowledge between consumers, rehabilitation engineering centres and Federal research and development laboratories has been established in the USA: the Consumer Assistive Technology Transfer Network.[63] People with disabilities and those caring for them have collaborated with assistive technology programmes, engineers and researchers to solve practical problems with assistive technology devices. Assistive technology devices were defined as any item, piece of equipment or product system, whether acquired off-the-shelf, modified or customised, that is used to increase, maintain or improve the functional capacities of an individual with a disability. The Network included 56 assistive technology centres (one in each State), 16 rehabilitation engineering centres and over 600 Federal research and development laboratories. Collaboration was through end users being members of the advisory board, and through ongoing mechanisms for addressing consumer requests and researcher responses to assistive technology problems. The Internet provided vitally important communications for the Network. Its multimedia capabilities were especially valuable for people who had difficulties with vision, hearing, speech and/or mobility.

Some practical problems were solved by identifying suitable devices, some by amending or combining devices and some by research and development. Solutions have helped a man with cerebral palsy wishing to officiate baseball games, improved communication devices and improved light weight and durable mobility devices (wheelchairs, canes, crutches and walkers). Each of these scenarios was described from both the developers' and consumers' perspectives. Developers and researchers have gained from having consumers define problems and test prototype solutions. Consumers have benefited by acquiring solutions to their practical problems. Additional benefits have come in the shape of development funding, which has sometimes been secured through disability-related laws enshrining independence and equal participation in society. This investment was supported by the technological advances of the Internet and laws which could secure funding and protect research and development in the commercial sector. The report presented a vision (and routes for achieving this vision) of independent lifestyles in terms of family, homes, telephones, jobs, school and leisure pursuits and this brought a humanity to the report.

- The Alzheimer's Society, although established by a consumer in 1979, 20 years later was funding research largely on the basis of professionals' decisions. Broader involvement of carers and people with dementia began with an invitation circulated by newsletters and the Internet.[64,65] Respondents have been coordinated through the Quality Research in Dementia Advisory Network. Support and training were available to carers before they were involved in prioritising research topics and commenting on research proposals. Ideas for research from 150 carers and people with dementia were posted on the Internet and researchers applying for funding were asked to consult this list before submitting their proposals. Further details are reported in Chapter 5.

- CABI-Bioscience, an international organisation, originated in London. Their Integrated Pest Management programme employed an action research model in developing countries. Local farmers were trained through discovery-based learning, to choose topics for research, and then carry out their own research projects.[66] In Kenya they have experimentally evaluated different methods for controlling pests. This was a fundamental change to traditional education and support methods. Some staff felt the pressure to supply ready-made advice and complete answers. They found it difficult to admit to farmers that they did not know the answers. Further details are reported in Chapter 5.

Reviewers' commentary
Advantages of collaborations for individual consumers were broadly similar to those identified for the collaborations with consumer groups. Ongoing relationships between consumers and researchers[63,67] and empowerment and partnership benefited consumer involvement.[62,63] Far fewer examples were found of individual consumers/users or members of the general public being involved in collaborations, than of consumer groups.

Two exceptional examples involved considerable investment in establishing an infrastructure. One was an Internet network that facilitated communication between consumers, service

providers, product developers and researchers.[63] In all of these examples consumers are involved not just in identifying topics for research, but also in conducting research and evaluation themselves. Rather than merely identifying the questions, they could look forward to finding some answers. Another was a charity that invested in training and communication to involve carers in setting priorities and peer reviewing research.[65]

Success in identifying consumers' priorities through participative training and research requires particular skills for providing support and letting consumers take the lead rather than employing didactic methods to educate consumers.

Key messages
When research programmes invited individual consumers to collaborate:

- Training, education or 'knowledge transfer' was an integral part of all examples.[61–64,66]

- The exercise required investment of time, resources and personal relationships.[61–63,66]

- There was the motivation of finding research-based answers, not just identifying the questions.[61–63,66]

- Topics for research were identified by consumers who were empowered to learn from the collaboration.[61,62,66]

- Participative training methods provided a learning experience for trainers too, and sometimes changed their attitudes.[62,66]

Details of Type C approaches are given in *Table 3*.

TABLE 3 *Type C Inviting individual consumer involvement through collaboration*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
C.1 Teamworking							
Schwab, 1997[61]		Young people from low-income families	Teamworking – participatory action research	Empowerment/ partnership/power sharing	Young people selecting and framing own issues for research	Increased self-esteem, social awareness and social responsibility	Description by participant researchers/ managers
Glanz and Neikrug, 1995[62]	Gerontological research	Older people	Training programme	Empowerment	Older people doing own research; articles published in journals	Mutual learning	Description by participant researchers/ managers
Newroe and Oskarsdottir, 1997[63]	Consumer Assistive Technology Transfer Network	Disabled people	Committee membership	Consumerism, partnership	Consumers defined problems and tested prototype solutions	Independence and equal participation values; end users involved in advisory board	Description by participant researchers/ managers
Alzheimer's Society, undated;[64] Harvey, 2000[61]	Alzheimer's Society	Alzheimer's patients and carers	Written consultations, workshops	Empowerment	Consumer priorities posted on Internet to inform research grant applicants	Integral training programme	Description by participant researchers/ managers
Kimani et al., undated[66] *Case investigated in more depth for UK episodes (see Chapter 5)*	*CABI Bioscience – Integrative Pest Management*	*Farmers*	*Farmer participatory training and research*	*Participatory research*	*Farmer identified research topics. Farmers become 'active learners'*	*Farmers become 'active learners'; time-consuming*	*Description by participant researchers/ managers. Interviews with participant researcher/manager*

Type D: inviting involvement of individual consumers through consultation

Where research programmes consulted individual consumers, we designated it as Type D engagement (*Figure 6*). We found that consumers have been invited to participate in setting research agendas through written consultations, face-to-face discussions or a combination of the two.

We defined individual consumers as individuals who were not representing consumer groups. They were service users, patients or carers – people whose lives are directly affected by a particular condition – or they were members of the general public.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type D approaches to consumer involvement.

D.1 Opinion surveys

Opinion surveys sought opinions on pre-set statements or questions about priorities for research.

- Surveys have been conducted simultaneously in the 12 countries of the European Community in 1991, 1993 and 1996.[68] They aimed at a better understanding of European opinion on biotechnology. The 1993 survey focused on seven different themes:
  1. expectations regarding biotechnology and other new technologies such as computer science and space exploration
  2. knowledge (both 'objective' and 'subjective') of biotechnology
  3. attitudes and opinions on diverse applications of biotechnology
  4. information sources that people use to draw their knowledge on 'the new developments which affect our way of life'
  5. information sources on biotechnology that people trust
  6. biotechnology and questions of ethics
  7. influence that persons or groups concerned about the potential risks associated with

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A	Type B	
	Inviting individual consumers		Type C	Type D: opinion surveys, small and large face-to-face encounters	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

FIGURE 6 *Framework for describing Type D consumer involvement in research agenda setting: inviting individual consumer involvement through consultation*

advances in biotechnology and its diverse applications can actually have on this development.

In each country, these questions were asked of a representative sample of the national population aged at least 15 years old. In total, 12,800 people were interviewed. Together these surveys provided standardised information about attitudes towards particular applications of biotechnology (food, plants, medicines, basic research, transplants and genetic testing) and priorities for research and development.

This approach did not reveal suggestions for research topics. It did indicate an order of preference for encouraging R&D. In decreasing order of priority, this was testing for genetic diseases; genetically engineering medicines; developing pest-resistant crops; developing genetically modified animals for laboratory research; developing genetically modified foods; and genetically engineering organs in animals for transplant into humans.

- Much smaller surveys conducted in Japan[69] between 1991 and 1993 sought the opinions of members of the public, high-school biology teachers, scientists and nurses about *in vitro* fertilisation, genetic engineering and biotechnology. Questionnaires to the public were distributed by hand into letter boxes chosen at random in different areas of Japan, and mail response was requested with an enclosed stamped, addressed envelope. The potential respondents' names and addresses were not written or recorded so no reminders could be sent. This method was chosen to ensure that there were no fears about privacy, and for its low cost, but the authors considered this to be the cause of the low response rate of 26%. This method captured quantitative data about public perceptions. For instance, among the public respondents who had heard of *in vitro* fertilisation, 58% saw it as a worthwhile area of research, less than all other developments.

The authors concluded that:

> "The emotions concerning these technologies are complex, and we should avoid using simplistic public opinion data as measures of public perceptions. The level of concern expressed by scientists and teachers in Japan suggests that public education 'technology promotion

campaigns' will not reduce concern about science and technology. Such concern should be valued as discretion that is basic to increasing the bioethical maturity of society, rather than being feared."

Reviewers' commentary
Opinion surveys[68,69] have the advantage of targeting a broad range of people who can be randomly selected in order to represent whole populations. Both of these documents described international opinion surveys aimed at the general public. Advantages of this method may be the scale, the numbers of individuals consulted and the comparability of the attitudinal data from nine EU countries.[68] Disadvantages may be the limited nature and understanding of that data, with no communication, feedback or ongoing involvement for the respondents. This method does not identify research topics but may identify broad attitudes (in this case perceived favourable and unfavourable areas for biotechnology and genetic engineering research evidence) that can be applied in priority-setting exercises.

D.2 Face-to-face encounters on a small scale
We found interactions where individual consumers, rather than members of consumer groups or consumer representatives, were consulted face-to-face to set research agendas for specific issues: school health,[70] environmental conservation,[71] prostate disease,[72] arthritis,[73] service delivery and organisation[74] and devices to help people with disabilities.[75–78]

- A literature review and face-to-face consultation exercise were conducted in 1997 to develop an evaluation plan for school health programmes in Nebraska, Canada. This priority-setting exercise was set against a background of increasing financial constraints.[70] "At the same time that public funds to support programs [had] continued to shrink, new legislation and policies [had] been enacted requiring public sector agencies such as schools to plan and report outcomes associated with program implementation." The literature review revealed little information about what most legislators, school boards and parents wanted to know about the impact of a health programme and little evidence of the community having been included previously in the evaluative process. To design the plan for school health programme evaluation, a group of stakeholders was assembled to obtain community input.

Stakeholders were identified as those community members who had a vested interest in the outcome of the school's health activities. The group was limited to 10 to facilitate discussion and consisted of two teachers, a principal, a school nurse, a custodian, a dietician, a student, a counsellor, a parent and a state legislator. Focus group discussion and a prior questionnaire considered (a) what key questions needed answering to judge the value of their school's health programme, (b) what questions other tax payers in their district would want answered regarding the effectiveness of school health activities, (c) which individuals should be responsible for conducting an evaluation of the school's health programme and (d) specific indicators for subjective or objective measurement. The final evaluation plan was developed and implemented as a State-wide evaluation of comprehensive school health services.

• Madagascar's biodiversity is of extremely high international significance, yet comprehensive efforts to assess current knowledge and set priorities have been absent until recently. A major participatory effort to assess the country's scientific and conservation priorities began in 1995.[71] A scientific workshop with over 100 experts set biodiversity priorities for the island. A principal finding of the workshop was that many areas of outstanding biodiversity and research importance are located outside protected areas. Workshop participants also agreed that corridors needed to be created between the high-priority protected areas in order to maintain gene flow and exchange of species. The second stage of the process was a stakeholder consultation that integrated scientific findings, national priorities, local stakeholder views and donor input. "Local resource users" included farmers, ecotourism operators and forest-product gatherers. They identified "environmental problems and possible solutions" through interviews. Stakeholders at regional level further prioritised problems and possible solutions. The net result of the process was the adoption of a landscape approach to conservation that integrated regional planning, biodiversity monitoring and institutional strengthening.

• The US Patient Outcomes Research Team (PORT) strategy led to programmes designed to provide a mechanism to ensure systematic evaluation of all relevant treatment theories, not just those that are for regulation purposes or those of particular interest to investigators. In the 1980s the Prostate Disease PORT saw its first task as "learning what mattered to patients and to develop an instrument that captured the events".[72] They undertook "unstructured interviews with patients (using a focus group format) … [and] amassed a list of outcomes that mattered to patients and then set out to build and validate a questionnaire to quantify symptoms, complications and quality of life states and to measure the subjective impact that the … condition had on the individual patient – how much he was bothered by his symptoms and what his expectations were from treatment." Subsequently, 400 patients were interviewed. The research team learnt that "most patients, including those with less than high school education, want considerable information and feel this experience is valuable in making a treatment choice". On the basis of this work, they planned a technology assessment network to gather evidence for all the treatments available for prostate disease in terms of outcomes that matter to patients, and to facilitate informed patient choice. This plan foundered after its pilot work through lack of funds.

• Face-to-face consultation with patients was also employed by the NHS Advisory Group for Asthma (described in Section B.4). No details of the process or outcome were reported.

• A study of arthritis of the knee compared the current evidence base for treatment with the views of arthritis patients. Focus groups and a questionnaire for arthritis patients were conducted to establish what treatments they had tried to alleviate their suffering and which treatments should be prioritised for research.[73] A comparison with the evidence base for the effects of these treatments concluded that the current research agenda did not match current treatment patterns and consumer needs. Current evidence focuses on drugs and surgery. Patients would like all treatments to be evaluated, including education and advice, physical therapy and complimentary therapy. Although the findings have been disseminated by publication in *The Lancet*, this exercise was not directly linked to the commissioning of research.

Reviewers' commentary
Consulting individuals made it possible to draw opinions from a broad range of people who were

not necessarily actively involved in consumer groups. This was applied to gauge views within a nation,[71] views of people using particular services[70] and products[72,73,75–79] and the views of patients recruited from clinical settings.[72,73]

Recruiting patients from clinical settings for focus groups and questionnaires had the advantage of including a broad range of people, specifically not excluding those who were less educated.[72]

For organisational research, purposeful sampling of individuals with service provider and client roles was more appropriate. This has provided a team for designing a service evaluation programme that could be widely implemented.[70] However, there was no record distinguishing the views and contributions of providers and clients. Similarly with environmental research, conservationists and resource users collaboratively set a research agenda, but we have no indication of how views varied or how consensus was achieved.[71]

Unless setting the agenda was part of a larger commitment to conduct research,[70,71] practical difficulties such as lack of funding or links with a research programme could reduce setting the research agenda to a largely theoretical exercise.[72]

D.2b Face-to-face encounters on a small scale in commercial settings

A variety of small face-to-face encounters have been reported in the literature about setting research agendas for assistive technology devices.[75–78] These involve consumers in innovative development and evaluation. The methods they used included focus groups for 'brainstorming and prioritising',[75] combining focus groups and surveys,[76] a focus group process based on a modified version of the Delphi method,[78] and the Kano focus group model.[77]

These enterprises rested on theories of consumerism[76] and "the expanding variety of assistive technology devices from medical instruments to consumer product". Their changing image coincides with consumer-directed efforts to shift the orientation of service programmes from a medical model to a consumer model. Under a consumer model, manufacturers and suppliers in the marketplace

compete to deliver the most useful product in the most efficient manner possible. Understanding consumer behaviour is critical to providing competitive products in the marketplace. Examples of innovative approaches to involving consumers are described below.

- The Rehabilitation Engineering Research Center on Technology Evaluation and Transfer in New York employed the Kano focus group model where consumer perspectives were first introduced at the stage of designing 'probing questions' for a focus group.[76,77] Typically teams designing these questions included an engineer, a marketer, a knowledgeable end user, the focus group moderator and an expert in qualitative data analysis. The team would draw upon personal experience, standards, consumer reports, academic research, market research, industry and consumer interviews to write the questions. The aim of the focus group discussion was to identify three types of product requirements: expected, revealed and exciting. The most basic were unspoken requirements of products that were 'too obvious' to mention: 'expected requirements'. Requirements that were normally spoken of and referred to as day-to-day concerns that seemed important were 'revealed' requirements. Previously unknown concepts or those that might appear 'too far fetched' were the 'exciting' requirements. Generally, a product design that does not satisfy expected requirements fails in the marketplace. A product redesigned to incorporate revealed requirements is evolutionary and should retain or increase its market share. A product design incorporating exciting requirements is revolutionary, with potential to become a market leader. Probing questions were considered especially useful for introducing focus group participants to exciting product requirements represented by new technologies and technological concepts. Systematic preparation of probing questions also lessened the likelihood that critical expected requirements would be overlooked. Following an analysis of the focus group statements, surveys were then developed to establish the importance and priorities of the product requirements derived from the focus groups. In this instance, consumers placed the highest importance on the three evaluation criteria of physical security and safety, product reliability and effectiveness, and the implications of these were made clear for product designers. The authors reported the

development examples of wheelchair tie downs[77] and battery chargers.[76] In each case 100 experienced users rated over 150 statements pertinent to the ideal product and rated the 11 evaluation criteria. The authors expected the findings to guide the development of better products.

- The panel members for a modified Delphi method were not statistically representative of the disabled population. Rather, they were a hand-picked group of analytical and articulate long-term users of assistive devices with a variety of disabilities.[78] As such, they could "provide valuable insight into the evaluation factors used by one group of disabled persons whose members have given careful thought to how assistive devices should be designed, manufactured and selected". The basic premises of this consumer-based evaluation theory were that (a) the consumer, the disabled person who has used a device, must be the ultimate evaluator of whether a device is satisfactory, and (b) the consumer who has used the device for an extended period of time is in the best position to offer factors to be considered in developing normative evaluation criteria for the device.

- 'Quality function deployment' is the name of a process in which the voice of the consumer is deployed throughout the R&D, engineering and manufacturing stages of product development.[79] Individual and focus group interviews have been used to guide the development of consumer products in the USA and Japan. Their research concluded that (1) one-to-one interviews may be more cost-effective than focus groups, (2) interviews with 20–30 customers are necessary to identify 90–95% of the customer needs and (3) multiple analysts or team members should read and interpret raw transcripts.

- Involvement of consumers in identifying R&D priorities for power wheelchair input devices and controllers has been justified by the notion of the 'smarter wheelchair', which has a smarter, more dynamic process between the user and the technology.[75] There was an assumption that if an awareness of users' feelings and perceptions was present before and during the design stage, the resulting technology should have a better chance of success because useful features would be available and the user interface would facilitate easy setup and operation.

In a 'consumer-responsive development process', brainstorming and five rounds of voting led to five priorities:
1. durability and reliability
2. user adjustable and programmable
3. standard power take-off port
4. availability of alternative modalities for feedback and user
5. emergency sensors for tilt, obstacles and stairways.

Reviewers' commentary
The aim of these interactions was to achieve new product success and more profitable products. They rest on the assumption that a greater awareness of users' feelings and perceptions of technology leads to a greater likelihood of successful technology with benefits for people with disabilities and assistive technical device producers.[75]

These interactions differed from those which we found in the public sector. They purposely recruited atypical consumers who were knowledgeable, analytical and articulate. They purposely sought high consumer expectations and tried to meet them. They invested in an infrastructure of consumer testing sites and teams of consumers and analysts to capture consumer concerns.

Face-to-face interactions with individual consumers were reported with more emotive language. They had the potential for a greater immediacy and potential for fundamental changes in attitudes. Researchers talked about users' "voice"[79] and reported how working with consumers "deeply influenced our thinking",[72] gave them a "greater awareness of users' feelings and perceptions"[75] and outlined the impact of consumers on priorities in terms of "breaking institutional preconceptions of problems and aiding new solutions".[71]

D.3 Face to face encounters on a large scale
Face-to-face encounters on a large scale included town meetings and consensus conferences. In America, NIOSH published its research agenda in 1996[54] (see Type B.3). Consensus conferences have a more standardised format and have been described as:

"a public enquiry at the centre of which is a group of 10–16 citizens who are charged with the assessment of a socially controversial topic of science and technology. These lay people put their questions and

concerns to a panel of experts, assess the experts' answers, and then negotiate amongst themselves. The result is a consensus statement which is made public in the form of a written report at the end of the conference."[80]

- The advantages of broader representation in terms of face-to-face multiple interactions were addressed by a review of consensus conferences on public participation in science.[80] Advantages of involving members of the general public were expressed in terms of informed debate and participatory democracy, attributed to the dialogue encouraged between scientists and the public and lay perspectives being brought into decision-making. Similar advantages are claimed for citizens' juries (smaller counterparts of consensus conferences).[19] Neither method has been employed for the purpose of identifying research topics, but research topics have emerged where members of the public have been encouraged to seek research evidence on which to base their decisions, and have been unable to find the evidence they needed.

Reviewers' commentary

Although consensus conferences or their smaller counterparts, citizens' juries, have not been convened for the purposes of setting research agendas, debate has revealed topics which needed more research.[19,80] However, these ideas may not be captured while conferences are convened under the banner of public understanding of science where they involve consumers in debate focusing on the impact of science on decision-making rather than considering the impact of consumers on science.

D.4 Combining written consultations with face-to-face encounters

- The NHS Service Delivery and Organisation (SDO) research programme combined written consultations with face-to-face encounters. There were no sufficiently detailed reports for inclusion in the literature review, but further details can be found in Chapter 5.

Key messages

When research programmes consulted individual consumers:

- Little is known about how consumers view consultation of individuals because all of these documents have been written from the research perspective,[60,68–79] with the exception of a report of consensus conferences,[80] which was written from both research and consumer perspectives.

- Even less is known about consultation of individual consumers in the UK as all these reports are from abroad.[68–73,75–80]

- Commercial interests which involved consumers as partners were particularly successful in capturing and making use of consumers' ideas and priorities. Their motivation for investing in consumer involvement was a greater market share through more advanced technologies and a greater profit.[75–79]

- Least was learnt when research programmes perceived consumers primarily as users of research.[72,80]

- Opinion surveys gave a broad but shallow picture of attitudes, perceptions of benefit and harm of research, and limited data about research priorities or reflection about the process of involvement owing to the 'closed' questions.[68,69]

- Patients recruited in clinical settings have been interviewed to identify interventions[73] and outcomes[72,73] to frame evaluation agendas.

- Involving individuals with personal experience of problems has sometimes added an immediacy to the debate which is sometimes expressed in emotive and persuading language, and could be particularly thought-provoking for researchers.[72,75,79]

Details of type D approaches are given in *Table 4*.

TABLE 4 *Type D Inviting individual consumer involvement through consultation*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
D.1 Opinion polls							
European Commission, 1993[68]	European biotechnology	Representative sample over age 15 years	Opinion poll in 9 EU countries	Bioethics	Public's preferences for biotechnology identified	Random sampling. Closed questions. Wide scope/comparability of data. Limited data in terms of research priorities	Description by participant researchers/ managers
Macer, 1994[69]	Public attitudes towards IVF, genetic engineering, biotechnology	Representative sample	Opinion poll	Bioethics	Public's preferences for biotechnology identified	Random sampling. Closed questions. Wide scope of consultation. Simplistic data	Description by participant researchers/ managers
D.2 Face-to-face encounters on a small scale							
Cramer and Iverson, 1999[70]	Nebraska School Health	'Stakeholders' including student, parent	Prior questionnaire to participants to prepare them for focus group discussion	Health promotion/ community development; public accountability	Research agenda published without detailing consumer contributions	Community/stakeholder participation. Gauging views of those with 'vested' interests. Planned consumer participation in evaluation	Description by participant researchers/ managers
Hannah *et al.*, 1998[71]	Conservation in Madagascar	Farmers, ecotourism operators, forest gatherers	Interviews and stakeholder workshop	Consensus development	Identified research needs without detailing consumer contributions	Broad range of participants. Large-scale participatory effort. Gauged regional view. Helped break institutional preconceptions of problems – new solutions	Description by participant researchers/ managers
Wennberg *et al.*, 1993[72]	Prostate Disease PORT	Patients with experience of the disease	Focus group	Evidence informed patient choice	Research agenda published without detailing consumer contributions	Involvement of patients in identifying information needs. Professionals learning from patients – "deeply influenced our thinking". Gauged regional view through direct service users	Description by participant researchers/ managers

TABLE 4 *Type D Inviting individual consumer involvement through consultation (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Department of Health, 1995[60]	NHS R&D Asthma	Patients	One-day workshop	Organisational change	Suggested problems needing R&D		Description by participant researchers/ managers
Tallon *et al.*, 2000[69]	Contract researchers	Patients with arthritis	Focus groups and questionnaire	Evidence informed patient choice	Consumer-identified priorities	Involved patients with direct experience. Low consumer response	Description by participant researchers/ managers
Lane *et al.*, 1997[76] Stone *et al.*, 1998[77]	Rehabilitation Engineering Research Center on Technology Evaluation and Transfer	'Experienced' technology users	Focus groups, (Delphi) survey – "capturing consumer voice" through Kano focus group	Organisational change Consumerism, partnership	Consumer priorities for criteria for evaluation	Gauged regional views through 14 testing sites, focus groups and survey. Criteria for development set by consumers, circulated among experts	Description by participant researchers/ managers
Batavia and Hammer, 1990[78]	Rehabilitation Engineering Research	All users of AT devices on panels	Face-to-face: modified Delphi method	Consumerism, partnership	Evaluation criteria incorporated by research programme	Consumer-driven prioritisation exercise. Assumed end users must be ultimate evaluators of whether a device is satisfactory	Description by participant researchers/ managers and consumers
Griffin and Hauser, 1993[79]	Engineering product development	Individual product users	Various face-to-face multiple	Consumerism, partnership	Evidence about methods for involving consumers	Gaining the customer voice was part of product design and evaluation. Model for achieving new product success and more profitable products	Independent review
Brienza *et al.*, 1995[74]	Power wheelchair development	3 out of 7 in the group were individual wheelchair users	Face-to-face: result of brainstorming of issues, multivote and ranking of priorities	Consumerism, partnership	5 priorities set	Equal participation of consumers and professionals. Mutual benefits for consumers and producers. Assumed greater awareness of users' feelings leads to greater likelihood of successful (+ profitable) technology	Independent review

continued

TABLE 4 *Type D Inviting individual consumer involvement through consultation (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
D.3 Face-to-face encounters on a large scale							
Joss and Durant, 1995[80]	Various authorities	Members of the public	Consensus conference	Participatory democracy	Few research topics identified	Dialogue between scientists and the public – clarity of language and concepts by panellists. Focus on appropriate impact of science on society rather than impact of public on science	Independent review
D.4 Combining written consultations with face-to-face encounters							
Dalziel and Fulop, 2000[74] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D SDO*	*Consumer groups, patients and carers*	*Focus group*	*'Listening'*	*Research agenda published without detailing consumer contributions*		*Interviews*

Type E: responding to consumer action with collaboration

Where research programmes responded to consumer action by collaborating with consumers, we designated it as Type E engagement (*Figure 7*). We found research programmes that have responded to consumer group attempts to influence research agendas (advocacy and campaigning) through various forms of committees involving consumers and through teamworking. Although the methods employed for the interactions may be the same as in Types A–D (e.g. committee membership and teamworking), when the issues have been raised initially by consumers, and the consumers and research programmes have engaged as a result of strong campaigning, the balance of power between the two may be different and for this reason we have reviewed them separately. Research programmes responding to consumer groups with a collaboration were generally seen as successes from the consumer perspective.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type E approaches to consumer involvement.

E.1 Teamwork

The late 1990s in New York saw strong advocacy for the needs of homeless people and a dramatic growth of homelessness research. A homelessness research programme provided the first systematic assessments of consumer and provider preferences regarding the content of research about homelessness.[81] In the winter of 1996–97 they involved clients and staff at a veterans project in the selection and prioritisation of research topics. Working methods emphasised collaborative and non-hierarchical relationships between researchers and other participants. Research topics were identified through a 15-item questionnaire to 87 clients and 28 staff, requesting the five most and five least important research topics. Staff and clients differed significantly on six items considered most important and four items considered least important. Clients wanted more research that focused on material needs. Appreciable data already exist for many of the topics requested, raising concerns about the accessibility of homelessness research, and the need to combine consultations with literature reviews.

E.2 Multi-level participation designed in partnership with consumers

Some programmes incorporated consumers throughout their work with multiple advisory structures.[82,83]

Researchers' degree of engagement		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
	Inviting consumer groups		Type A	Type B	
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

Type E: committee membership, teamworking, multilevel participation, community-based research

FIGURE 7 *Framework for describing Type E consumer involvement in research agenda setting: responding to consumer action with collaboration*

- The National Breast Cancer Coalition (NBCC) has described how its campaigns in the USA led to a National Action Plan.[84,85] In 1991, the NBCC orchestrated the delivery of 600,000 letters to the House of Congress and the President, convened 'research hearings' with 15 prominent scientists in Washington and coordinated 38 events in 31 states during Mothers' Day weekend in 1992. This led to vast increases in funding for breast cancer research: US$132 million for breast cancer research to the National Cancer Institute in 1992 (almost a 50% increase on the previous year's spending), $210 million from the Department of Defense and $200 million to the National Institutes for Health (NIH). Further media attention, letter-writing campaigns, a nation-wide petition and another Washington march preceded a conference in 1993 convened to design a national action plan for breast cancer. Breast cancer advocates, members of Congress and of the Administration, the scientific community, private industry and the media met to share ideas and reach consensus on the elements of a strategy to end breast cancer.[84] Objectives addressing research were to "include consumers at every level of the decision-making process".

- This story is continued from the perspective of the Department of Defense Breast Cancer Research Program[86] with a description of how "consumers sit side-by-side with scientists in setting research priorities". The programme acknowledged that this innovation was a direct result of pervasive, persistent and highly visible grass-roots lobbying. The programme funded research responsively through a two-tier scientific review system. In the first-tier, discipline-specific peer review panels assess the scientific and technical merit of proposals. In the next tier, an independent review group, the Integration Panel, reviews meritorious proposals and recommends funding of those submissions that best meet the programme goals and advises the Department of Defense in identifying gaps in research. Consumers were initially only on the Integration Panel but in 1995 their role was expanded to include participation as reviewers on scientific peer review panels. By 1998, 318 consumers had served on over 150 review panels contributing their expertise and first-hand experiences, "ensuring that the human dimensions of breast cancer are fully incorporated into decisions about research funding". Following evaluation of the initiative, consumer involvement in scientific review was incorporated into all research programmes conducted by the Department of Defense Congressionally Directed Medical Research Programs.

  "Organisation and commitment to the goals of consumer involvement were critical … the introduction of change in the traditional scientific review process by this novel program was met with scepticism and some resistance. These issues were addressed throughout the program's history. Four major factors were essential in meeting this challenge: (a) effective program management, (b) a process of improvement focus, (c) firm leadership, and (d) the allocation of sufficient resources."[86]

  A consumer working group played a crucial management role, establishing clear goals and core objectives, prioritised programme functions, developed and organised procedures and processes, motivated and built consensus amongst participants and designed systems for feedback and analysis. Ongoing review and analysis of the programme by the consumer working group, and documentation of the programme modifications, led to a model programme which has since been adapted to other settings.

- Women in breast cancer groups in California campaigned for and helped write the legislation for the Breast Cancer Act of 1993, which led to the setting up of the California Breast Cancer Research Program.[83] The Breast Cancer Research Council was composed of breast cancer survivors and related advocacy groups (one-third of the members), clinicians and scientists (one-third of the members) and representatives of non-profit health organisations, private industry and practising breast cancer clinical specialists; and women with breast cancer have chaired or vice-chaired the council. In 1996, the programme held a Public Advisory Meeting with representatives of academic research scientists, biotechnology researchers, clinical scientists and practitioners, healthcare providers, voluntary health organisations, community-based agencies and breast cancer advocacy organisations who were invited to develop its funding priorities. These priorities included an emphasis on "innovative and creative research, especially on research that complements, rather than duplicates, research funded by the Federal Government or other agencies". This involvement was summarised as a "pyramid of influence" of consumers within the programme.

- The Canadian Breast Cancer Initiative was described by the research programme as a participatory research approach where the catalyst for consumer involvement was grass-roots campaigning. They described their participatory research as: "(a) extensive collaboration between traditionally defined researchers and the community in each stage from identifying the problem to applying and disseminating the results; (b) a reciprocal educational process between community and researchers; and (c) an emphasis on taking action on the issue under study."[82] The National Forum on Breast Cancer, held in November 1993, was the first major activity of the initiative. Women affected by breast cancer were involved on the organising committee and on various sub-committees and working groups developing background information and materials for the Forum. Approximately one-quarter of the 650 invited participants were women and their families, the remainder being clinicians, researchers, representatives of non-government agencies and policy makers. "The concerns of women dealing with the day-to-day reality of breast cancer were articulated clearly in presentations by breast cancer survivors in the plenary sessions as well as in the small group discussions, in which all participants reviewed and refined the initial sub-committee recommendations." Thus the community made its voice heard. Areas of research that were strongly identified at the Forum included the psychosocial support of women with breast cancer and their families, the study of potential environmental causes of breast cancer and the effectiveness of alternative therapies.

Recommendations of survivor participants at the Forum led to the setting up of the Canadian Breast Cancer Network. This was a non-profit, charitable organisation that was a survivor-driven national network of organisations and individuals. The Cancer Network sought to promote education and communication about breast health, increase awareness of breast cancer as a major national health issue, increase openness and accountability in the research process, sustain a national network of breast cancer groups and survivors and help survivors develop support systems that meet their unique needs. Representation on the Breast Cancer Initiative committees was drawn from this network.

Key aspects seen by the Breast Cancer Initiative as likely contributors to the effectiveness of consumer participation included: involvement of all key stakeholders, including consumers, at a very early stage of the planning process 'without pressure from above'; being and being seen to be responsive to the identified needs of the consumers in a meaningful way; and including those stakeholders who can assist in implementing the final products of the Initiative. Challenges included those organisational pressures that influence the political will to involve and respond to consumers, the sublimation of science to the pressures of advocacy and the reality that the health of consumers may deteriorate at critical points during the process.

Reviewers' commentary

These breast cancer campaigns were examples of grass-roots advocacy. They differed from collaborations instigated proactively by research programmes (Type A) in that they led to fundamental changes in research funding structures. The Department of Defense breast cancer research programme differs from others we have reviewed in being a responsive programme. Rather than setting specific priorities for research, the funders invited suggestions from researchers. Prioritisation was through judging individual proposals.

Breast cancer advocates in all the multilevel participation examples described above were instrumental in designing a new programme rather than being recruited into an existing programme. The Canadian example was described by the authors as participative research. This differs from other examples of participative research, which more often were local rather than national in scale, and tended to involve consumers directly in conducting research rather than increasing openness and accountability in the research conducted by professionals. Both national and local examples of participative research emphasised a commitment to action.

E.3 Consumer activism leading to organisational change and multilevel participation

We found two examples of established research organisations responding to a culture of consumer activism by amending their working systems in order to attract broad consumer input into their work.[58,67]

- One such example in Australia entailed consumers being involved in setting a research agenda for breast cancer.[58] Consumers were

members of the advisory groups in the National Breast Cancer Centre and attended a consensus conference, in which consumer representatives – women with breast cancer – were equal participants in the process. The National Breast Cancer Centre in Australia worked "in partnership with women, health professionals, cancer organisations, researchers and governments to improve breast cancer outcomes for women". In 1996, the Centre held a consensus meeting to establish views about future research priorities and strategies for encouraging work in these areas. Care was taken in the choice of participants and procedures to reduce the possibility of bias. All groups to be represented at the meeting were identified at the outset and individuals selected to provide this representation. In this case, key groups included researchers, clinicians, policy makers, women with breast cancer and well women. Representatives of each group were required to have a comprehensive understanding of the issues, to be seen as peer leaders and capable of providing a wide view rather than focusing only on their own clinical or research areas. Background information was circulated 1 week in advance of the meeting, and a structured process involved an independent facilitator using a modified nominal group technique. Seven priority areas emerged from the discussion. Brief definitions for each area were written by subgroups of participants and were approved by the whole meeting. Although there was a high degree of consensus about the priorities, there was considerable disagreement about the value of ranking the seven priorities. The ethos of research programmes with a commitment to consumer involvement was recognised as an advantage in the report. It was felt that the Australian breast cancer programme "focused on the needs of the end user", because consumers were involved in the setting up of the research programme, and their involvement was incorporated throughout the advisory processes of the programme.

- In 1998, the US Institute of Medicine published an independent review of priority setting and public input at the NIH.[67] Congress requested this review against a background of NIH appropriating US$13.6 billion of the total $16 billion of public funds for research from the Federal Government. The review committee was to examine the criteria for allocating research funds, mechanisms for public input and the impact of congressional directives. The committee heard from NIH directors and legislative aides in key Congress offices. It also held a full-day public meeting at which members received written and verbal testimony from patients, advocacy and interest groups, foundations and professional societies. They recognised the frustration felt by some groups at not being listened to and heard by NIH, and found that some Institutes lacked mechanisms for orderly, regular public input and outreach. This frustration may have been compounded by the lack of transparency needed to satisfy people that allocation decisions were made on the basis of equity and justice, as well as scientific opportunity. A number of recommendations related specifically to public input, including:

1. More public members of the Advisory Committee to the Director, and greater involvement in the priority-setting process.
2. An Office of Public Liaison in the Office of the Director and … in each Institute office to document, in a standard format, their public outreach, input, and response mechanisms, with review by the Director's Office of Public Liaison to evaluate and identify best practices.
3. A Director's Council of Public Representatives … to facilitate interactions between NIH and the general public.
4. Public membership of NIH policy and programme advisory groups selected to represent a broad range of public constituencies.
5. Adjusted levels of funding for research management and support so that NIH can implement improvements in the priority-setting process, including stronger analytical, planning and public interface capacities.

Establishing an Office of Public Liaison was to facilitate and enhance a two-way communication with the public. Its key functions were to include: receiving input from a broader range of constituencies, disease-specific interest groups, and others …; organising this input to inform priority setting; documenting the ways in which this input is provided to those involved with NIH decision-making processes and NIH's responses to this input; involving NIH leadership in receiving and responding to input from the public; advising the Office of Communications so that NIH maximises its resources by providing information and programmes that are most responsive to the public; and evaluating all these activities.

The proposed Director's Council of Public Representatives would meet three or four times a year to advise the Director on how best to engage the public in priority setting, achieve broad representation for all public liaison, enhance public understanding of NIH, consider the health concerns of special populations, improve transparency and identify best practice for receiving public input and advocating their replication across the NIH.

Reviewers' commentary

From a consumer perspective, taking the initiative with campaigns and grass-roots advocacy has led to huge advantages of new programmes in which consumers were instrumental in establishing structures and procedures for ongoing involvement.[82–85,87] Reports prepared from a research perspective have also noted such advantages.[10,67,86] Consumer campaigns have also had some success in provoking changes within research organisations to increase consumer input.[58,67]

Consumers reported the debate as fully involving participants and attributed this to the choice of facilitator, a fellow consumer[37] on one occasion and an independent facilitator on another.[58]

E.4 Community-based research

- An example of community-based research was a study of child accidents and the maintenance of safety which ran alongside a parents' action group on child safety in Corkerhill,[88] Glasgow, Scotland. The community view was that

> "too often we have been subjected to the 'goldfish bowl' approach to research. We have been researched upon. The researcher selects the topic, studies his subject and returns to the lofty towers of academia leaving a bemused community who very soon realise that they have gained nothing from the experience … . If community research is to be meaningful it must be carried out with the full cooperation of the community in partnership with the academics. It must also address issues which are identified as prioritised by local people."

On this occasion, the community approached the researchers, who acknowledged that:

> "Research agendas do not drop from the sky, and … at the time the work was set up, child accident research did not have the priority which subsequently resulted from the publication of *The Nation's Health* (Department of Health, 1992). The research derived from anxieties parents felt about the safety of their children in Corkerhill."

Hence the topic of research went well beyond whether they would be run over by a car to include the lack of safe play areas. Instead, children played in cold, damp housing, residential entrance halls littered with needles and a run-down children's playground next to a main road as alternatives. As the community educated the researchers into the broad scope of child safety in unsafe environments, the researchers were able to bring to the community understandings about the role of social epidemiology in describing and understanding patterns of accidents and ways in which these could be used. The result was a community-led research programme and consequent health gains. Three times a week up to 50 children joined a 'Dangerwatch' scheme where, rather than being 'talked at' about safety, children were given the much more interesting task of identifying potential dangers in their homes, backcourts and streets. Also, Glasgow City Council invested £970,000 in a central heating system for Corkerhill. This was probably the result of a number of initiatives: the Corkerhill Damphouse inquiry; representations made by Corkerhill Community Council to the Scottish Office; and evidence from the accident prevention research on risks people perceived as being related to their damp housing. "While in traditional accident prevention terms, the installation of central heating might seem a long way from getting children to cross the road safely, from the tenants' perspective, a warm house is more likely to be a safer house for their children."

Reviewers' commentary

Most community-based research, like the example above, shares elements of participatory action research.

A very different model sprang from the collective social action of HIV campaigns. The campaigns of breast cancer activists described above seem mild in comparison with those of people with AIDS.

- "Never before have people with a disease organised so effectively to challenge government, the pharmaceutical industry, and researchers to change the way drugs are tested and approved."[89] AIDS spread rapidly amongst a population of young people who already had experience of organising themselves to fight discrimination based on their sexual orientation. People with AIDS built on this to plan traditional lobbying campaigns, made-for-the-media protests and civil disobedience to

gain public attention and appeal for US Federal Funding for AIDS research and education. They won scientific acceptance of and funding for a novel type of research, community-based clinical trials, by the Community Research Initiative in New York, where community physicians with AIDS practices planned clinical trials designed with patient input. In this way, community physicians could recruit patients to participate in research more easily, access to experimental drugs would be broadened and people with AIDS could exercise more control over what drugs were studied and how trials were designed, and thus would be more likely to follow trial protocols. The expectation was for quicker, cheaper research compared with the more usual large academic centres. Similar organisations developed in other cities. Federal funds were secured in 1989: US$9 million to 18 pilot programmes for community-based research in 14 cities, and a further $1.4 million was awarded by the American Foundation for AIDS Research.

One activist group, the AIDS Coalition to Unleash Power, developed 'The National Treatment Research Agenda' which called for sweeping changes in AIDS research and drug regulatory processes, including (a) broadening trial eligibility criteria so that most people with AIDS could enrol in trials, (b) permitting concurrent treatment to prevent opportunistic infections while enrolled in clinical trials, (c) involving people with AIDS in designing trials, (d) avoiding placebos and (e) not using death as the sole clinical end-point. A constructive response from scientists was to propose that the community-based clinical trial programme provide the infrastructure for conducting 'low-technology' trials which accommodated the first three demands.

- The story of a small-scale study of the relationship between HIV and suicide describes explicitly how the idea developed in London in the 1990s.[90] The UK Coalition of People Living with HIV and AIDS brought suicide to the attention of Members of Parliament, government officials, healthcare professionals and the HIV voluntary sector, highlighting the need for action and the urgency they felt. The increasing number of people attempting or succeeding in suicide was not anecdotal to them, but a reality. As front-line supporters they bore the burden of many people turning to them for information on effective ways to commit suicide or for a listening ear. Formal evidence was needed to justify resources to address the issue and this was the motivation for a collaborative study which brought together the HEA, researchers at the Royal Free Hospital, London, and people with HIV and AIDS.[91]

- The National Childbirth Trust (NCT) was a UK user group with 40 years' experience and approximately 40,000 members. It ran antenatal classes, breastfeeding counselling and postnatal support. Some of its members and staff were concerned about the conflicting information about breastfeeding given to women with flat or inverted nipples. They needed to know what treatment, if any, for flat or inverted nipples was worth recommending for women wishing to breastfeed. They approached the National Perinatal Epidemiology Unit for help. This research unit had also been approached by a midwife asking for help in extending a trial comparing treatments. As midwives and childbearing women had the same research agenda, they worked together to conduct a trial in which consumers were involved in the design of the study and the recruitment of participants.[92]

- A much younger and smaller consumer organisation has influenced the research agenda of the Royal College of Radiologists. In 1991, a legal report in the national press about a compensation suit for damages following radiotherapy attracted the attention of other women with similar injuries. Until then they had thought they were unique in sustaining severe and permanent brachial plexus injury following radiotherapy treatment for breast cancer. The women met and formed RAGE (Radiotherapy Action Group Exposure). This grew into a self-supporting voluntary group with the additional aim of campaigning for an investigation into the cause of radiotherapy injury in order to avoid future incidence and ensure that patients are warned of any risk. Public awareness grew and media interest during 1993 increased the list of RAGE contacts and members to 1500. RAGE reported how they advanced their cause through persistent pro-active campaigning and cooperation with the Department of Health and Royal College of Radiotherapists. As a result of a House of Lords debate, a committee was convened to consider how women with axial tunnel damage associated with radiation should be managed.[93] Four of the 14 members were consumer

representatives. RAGE consulted their own members about their injuries and their attempts to treat them and relieve pain. The findings of this consultation were included in the report published by the Royal College of Radiotherapists.[93] The same data from RAGE also informed an independent review commissioned by the Royal College of Radiologists, at the request of the Department of Health, into brachial plexus neuropathy following radiotherapy for breast cancer.[94] This report identified research questions about the impact of dose and application of radiotherapy. The work of the earlier committee led to a randomised controlled trial of hyperbaric oxygen with patient representatives actively involving the design of the study, recruitment, support of participants and monitoring of outcomes (Bradburn J, personal communication. Cancer Support and Information Centre, Mount Vernon Hospital, Northwood, Middlesex. 1997).

Reviewers' commentary

We found several examples of 'communities' identifying and prioritising individual research topics by drawing on their pooled experience: these topics were issues they faced in their daily lives, issues that defined the nature of the group. In each case, their achievement was seeing the research conducted, not merely identifying the research need.

Key messages

When research programmes respond to consumers' campaigns:

- Collaboration followed where there was a greater experience of consumer activism.[10,58,82–90,92,93]

- Formalised consumer involvement ensued on a grand scale where much of the dialogue was about the process of decision-making, in addition to the decisions, in research agenda setting.[67,83–87]

- Consumer groups proactively identify and prioritise individual research topics as part of their mutual support activities. These topics often reflect the issues that define the group.[89,90,92,93]

- Research with a consumer perspective has resulted from collaborating with geographical consumer communities[88] or special interest consumer communities.[90,93]

- Consumer activism has led to structural changes in research funding not seen in other types of engagement, or in the UK. Participative approaches to building research programmes on a national scale avoided 'tokenism' and were seen as successes by consumers and research managers.[82–86]

- In the UK, activism has not led to collaborative efforts to restructure research agenda-setting programmes, but to more modest individual research projects.[10,93]

Details of Type E approaches are given in *Table 5*.

TABLE 5 *Type E Responding to consumer groups with collaborations*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
E.1 Teamwork							
Cohen *et al.*, 1999[81]	Homeless research programme in New York	Advocates and individual homeless people	Teamwork – collaboration in conducting a survey	Equal partnership	Record of client and staff research preferences		Description by participant researchers/ managers
E.2 Multi-level participation designed in partnership with consumers							
The National Breast Cancer Coalition, 1994[84] and undated[85]	Breast cancer	NBCC in USA	Committee membership multiple	Consumers forced positive action; led to a partnership approach	Consumers secured extra funding for breast cancer research. National Action Plan aimed to include consumers at every level of the decision-making processes	Campaigns leading to summit and National Action Plan	Description by participant consumer group
Rich *et al.*, 1998[86]	Department of Defense Breast Cancer Research	Grassroots breast cancer organisations nation-wide	Committee membership, scientific peer review	Organisational change	Human dimensions of breast cancer considered in funding decisions		Description by participant researchers/ managers
California Breast Cancer Organisation[83]	California Breast Cancer Organisation	Breast cancer survivors and related organisation advocates	CI incorporated throughout programme – ongoing – "a pyramid of influence": consumer involvement through committee Chair, membership and public meetings		One-third of Breast Cancer Research Council consumer members (enshrined in law)		Description by participant consumers

TABLE 5 *Type E Responding to consumer groups with collaborations (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Parboosingh *et al.*, 1997[82]	Canadian Breast Cancer Initiative		Development of multiple levels of involvement in agenda setting at Canadian Breast Cancer Research Initiative, following consumer group advocacy	Participatory research approach	Survivor-driven national network of organisations and individuals established to, amongst other aims, increase openness and accountability in the research process	Consumers involved in setting structures	Description by participant researchers/ managers

E.3 Consumer activism leading to organisational change and multi-level participation

National Breast Cancer Centre, 1998[59]		NBCC in Australia	Committee membership and consensus conference	Ethos: consumer involvement throughout programme	Research agenda published without detailing consumer contributions	NBCC set up in response to consumer concerns. Criteria for choosing participants; independent facilitator; pre-reading sent week ahead. "Focused on the needs of the end user". Consumer identified and ranked topics. Informed debate. Full participation	Description by participant researchers/ managers
Institute of Medicine, undated[67]	NIH	Patients/their families and advocacy groups	Committee membership, liaison office; Director's Council of Public Representatives	Organisational change	Recommendations on processes for involvement and funding		Independent review by committee

E.4 Community-based research

Rice *et al.*, 1994[88]	Contract social scientists	Residential community	Community initiated research project – bottom up approach	Social action	Consumers identified issues and 'commissioned' researchers to do project	Greater shared knowledge and increased ability/confidence to participate in decision-making. "Stronger voice" to the community	Description by participant researchers/ managers and participant consumer

TABLE 5 *Type E Responding to consumer groups with collaborations (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Dunbar, 1991[89]		HIV activists	Partnership approach, following range of lobbying tactics	Social action	Community Research Initiative – one idea to design clinical trials with patient input	Prior activist experience	Independent unsystematic review
Campbell, 1995;[90] Scherr, 1995[91]		UK Coalition of People Living with HIV/AIDS	Collaborating with range of professional partners – HEA, Royal Free Hospital to set up team working on issue	Partnership (implicit)	Research project	Outcome of lobbying on suicide issues	Description by participant consumers
Renfrew and McCandish, 1992[92]	National perinatal epidemiology unit	National consumer group: NCT	NCT approached NPEU with research question – developed joint agenda		Completed randomised controlled trial	Shared learning	Description by participant researchers/ managers
Maher, 1995;[93] Bates and Evans, 1995[94]	Maher committee	National consumer group: RAGE	Committee membership		Independent researcher's review of interaction		Description by participant researchers/ managers and participant consumer

Type F: responding to consumers with consultation

Where research programmes responded to consumer action by consulting consumers, we designated it as Type F engagement (*Figure 8*). We found two examples of consultations mounted on a national scale in response to consumer activism.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type F approaches to consumer involvement.

- In the UK, widespread lobbying for improvements in maternity services indirectly led to consumer influence of the research agenda at a national and local level. This story has been retold from an American perspective.[10] A major government enquiry by the Select Committee on Health into maternity services coincided with an increasingly organised body of research evidence collated by the National Perinatal Epidemiology Unit, growing consumer activity led by national organisations and a more sophisticated political awareness of a major provider group, the Royal

College of Midwives. The resulting report advocated widespread change in the organisation of services and greater information and choice for childbearing women. "The Department of Health adopted classic bureaucratic strategies in responding … calling for more research, naming study groups, generally agreeing to the principles involved and promising little." It named a nine-member 'Expert Maternity Group' to continue the inquiry into maternity services, and this included a consumer group member, a journalist and a representative from the Asian Family Counselling Service. This group commissioned a national study of women's attitudes concerning their experiences with maternity services to inform their work. Their final report, 'Changing Childbirth', following a formal consultation period, provided a framework for national and local initiatives many of which involved either research into alternative systems for organising maternity care or assessment of the maternity care needs of women from different population groups. These projects often included consumers as active partners.

- In Canada, following intensive lobbying by a national coalition of women, the Government convened a Royal Commission on new reproductive technologies. This established a

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A	Type B	
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

Type F: political enquiries

FIGURE 8 *Framework for describing Type F consumer involvement in research agenda setting: responding to consumer action with consultation*

Consultation and Communications programme involving public hearings across Canada on issues which were to be reflected in the other stream of work, the Research and Evaluation programme.[95] The consultation included public hearings in 17 centres across the country, a national survey to 15,000 people and toll-free telephone lines for individuals to transmit viewpoints. There were also informal discussion groups for academics, practitioners and advocates together to develop a framework for research and development and identify research gaps. The Royal Commission allowed for "an arm's-length review of a contentious issue and [made] recommendations back to the government of the day". The report does not clearly record contributions made by consumers.

Reviewers' commentary
The two examples show how intensive and sustained lobbying by well-organised and politically astute consumer groups has led to public enquiries on a national scale. Both instances involved many consumer groups; the Canadian example involved a formal coalition of groups. Both ensuing consultations involved individuals and consumer groups and kept the issues in the public eye, but neither reports distinguished consumer contributions from those of others.

Key messages
The key message is as follows:

> UK
> - Well-established, politically aware consumer groups have sufficient critical mass to provoke sustained public debate and influence the research agenda.[10,95]

Details of Type F approaches are given in *Table 6*.

TABLE 6 *Type F Responding to consumer action with consultation*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Declercq, 1998[10]	Maternity care	National groups and individuals	NCT/AIMS campaigns – review of activities leading up to reform. Committee had one consumer group member	Social action	Consumers putting maternity care reform on to government agenda. Led to Department of Health Expert Maternity Group – Changing Childbirth Report	Conclusion of review: public interest groups can influence policy agendas	Independent review by researcher
Roberts 1999,[95]	Royal Commission for new reproductive technologies, Canadian Government	Coalition of women	Public hearings in 17 centres across Canada, national surveys to 15,000 people, toll-free telephone lines, informal discussion between academics, practitioners and advocates	Social action	Framework of R&D programme, but no analysis of the identified topics	Broad public involvement combined with advocacy contributed to review of contentious issues	Description by participant researchers/ managers

Type G: responding to consumer action with research

Where research programmes responded to consumer action by mounting research, we designated it as Type G engagement (*Figure 9*). The research provoked by consumer action may be about the topics raised by activists, or topics chosen in defence of consumer action. Alternatively it may seek consumers' views about research. Either way, we present here examples of consumer action indirectly influencing research agendas.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type G approaches to consumer involvement.

G.1 Provoking research about patients' views

- The power of a poignant personal message was apparent from the commentary on an essay by a Professor of English. George Zimmer was a cancer patient in Chicago. He participated in several Phase I cancer trials for ascertaining treatment doses and toxicity. His views appeared in a paper for which he was a posthumous co-author with his doctors in 1997.[96] He considered that:

" …important facets of the whole person are largely ignored when trial protocols are designed. … Patients who do seek to participate in protocols are those who question the status quo and those who are most eager to alter it. These useful traits often make them the despair of those who care for them because they question the programme in detail: they want to redesign the protocol to fit self-perceived needs. To a minor extent they often do succeed in having the protocol adjusted, thereby rendering trial results still more suspect.

"What would happen if a control group of more or less uncontrolled participants were permitted to change a protocol in radical ways? For example, if participants were allowed to combine substances as long as the combination was not known to cause death? Or, what if participants were allowed to increase drug doses as long as the amount was not known to cause permanent crippling? A hundred such patients might improve the chances of finding a cure a hundredfold… .

"That some of the 100 participants would die of the effects of their medication would be unavoidable – but better that a few fall in the storming of a bastion than no storming be attempted … . Letting a patient choose the poisons (under professional guidance) adds something to the will to struggle. We who are struggling to escape cancer do not obviously want to die of it. We do prefer death in the struggle to life under cancer's untender rule. The enemy is not pain or even death, which will come for us in any eventuality. The enemy is cancer and we want it defeated and destroyed …

		Consumers' degree of engagement			
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A	Type B	Type G: document analysis; public correspondence; lobbying/ campaigning
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

FIGURE 9 *Framework for describing Type G consumer involvement in research agenda setting: responding to consumer action with research*

"This is how I want to die – not a suicide and not passively accepting, but eagerly in the struggle."

He died of cancer approximately 6 months after writing his essay. His doctors were receptive to rethinking their approaches to research.

"His ideas are eloquently expressed and have had a profound effect on our investigational research for anticancer agents…. We must also listen carefully and thoughtfully to our patients. This is particularly true when, as research participants in the face of sacrifice and the threat of life-ending diagnoses, they have made the effort to express their concerns. On a personal level the essay by Professor Zimmer has had a significant effect on our research efforts. Thus it is with a sense of respect and honor that we share George Zimmer's thoughts and our comments about the influence he has had on our research practice."[96]

The researchers were influenced by this emotionally charged essay, but not sufficiently to abandon their reason. Rather than simply adopting George Zimmer's recommendations, they re-evaluated their views on Phase 1 cancer trials, and initiated a research programme to investigate to what extent his views were shared by other patients. Finding that most patients enter Phase 1 trials exclusively for therapeutic reasons, and not altruistic reasons, often ignorant of their investigative nature, George Zimmer's physicians conducted a feasibility study that attempted to incorporate the personal decision-making process of patients in Phase 1 trials and that allowed patients to determine the amount of risk they are willing to accept. The goals of this study were to increase patient understanding and autonomy through direct participation in research decisions and to increase patient satisfaction with clinical research.

- In 1997, 'Dolly' the lamb was the first successful cloning from an adult cell of a mammal. This was followed by a wave of concern expressed by political and religious leaders worldwide. The USA and the European Union both responded by commissioning a review of the ethics of cloning research.[97]

- Bombings, hunger strikes and death threats have been used to protest against the use of animal experimentation. A MORI poll was commissioned to ask a representative sample of British adults whether they supported or opposed each of a series of hypothetical experiments.[98] The wording of the questions was criticised for its bias and for the assumption that people's "gut reaction is based on misunderstanding".[99]

G.2 Research matching consumers' priorities

In contrast, when consumers expressed their research ideas in detail and in a medium familiar to researchers, there was a route to influencing subsequent research.[100,101]

- When mothers of hyperactive boys, following their hunch about a possible cause, substantiated their claim with a local survey and published their work in the academic literature,[100] they attracted the interest of scientists sufficiently motivated to investigate their research ideas further.[102]

- A letter from the NCT published in the BMJ[103] in 1990 refuted a consultant's claim[104] that there had been no published investigations concerning long-term problems associated with epidural anaesthesia in labour. Unsolicited reports of postnatal morbidity had prompted members of the NCT to undertake their own retrospective study of members' experiences. They had found long-term symptoms, including headaches, bladder problems, tingling or numbness, sensory confusion and, in particular, backache.[105] The letter called for "a prospective study of the administration of epidurals and care of anaesthetised women … to show the cause of injuries and indicate ways of avoiding them in future". The consultant criticised in the letter subsequently led a randomised controlled trial of two types of epidural analgesia evaluating short- and long-term outcomes including backache.[106] This trial was commissioned by the NHS Mother and Child Health programme as part of their priority for addressing interventions in labour – short- and long-term outcomes. It ran from 1997 until 2001.

- The Kendal Lakes Women Against Cancer Community Group has been described by Public Health and Oncology Consultants as typical of community responses confronted by medical environmental concerns.[107] In 1985, residents of this suburban community in South Florida became concerned when several young women were diagnosed with breast cancer. The women formed a community-based organisation to coordinate their community action and publicity. They had little or no prior experience of research, but their efforts led to an

epidemiological study undertaken by the University of Miami and funded by the State Department of Health and Rehabilitative Services. The aim was to find out whether some agent or toxic exposure existed in the community that may have caused breast cancer. Ultimately the study concluded that there was no environmental or chemical agent directly causing death in the Kendal Lakes Community and the consumer organisation disbanded. This episode was discussed in the context of a brief literature review. Other examples have shown harm; most notorious was the story of Love Canal where residents used community action, pressure and publicity to reveal high levels of benzene and other chemicals in their homes, and they were eventually able to relocate their families.[108]

Collective action resulting in research was not always seen as in the interests of the public. The authors interpreted other environmental research in Pittsfield, MA, as the US Environmental Protection Agency employing the 'need for further research' as a tactic to delay implementation of legislation to regulate the General Electric Company's production and disposal of polychlorinated biphenyls.[107]

The authors described how cases of community activism shared a basic pattern of activities: citizen identification of the problem; formation of an action-oriented group or committee; initial apathy of governmental or other official authorities; local or national publicity; development and implementation of an epidemiological or community-based investigation; and resolution of the issue. The authors considered this a rational community response to a threat rather than a panic reaction to be contained, and concluded that such community persistence, first by individuals and then as a group, has proven necessary in a variety of cases to address medical environmental issues objectively and systematically.

G.3 Research contradicting consumers' priorities

- Age Concern commissioned a survey from the Gallup Organisation to find out what women aged 65 years or over knew about the screening programme and risks of breast cancer.[109] Basing their case on this and their interpretation of professional research,[110,111] Age Concern criticised the current arrangements for

screening for breast cancer[112] and the government's proposal for two pilot projects to investigate screening for breast cancer in women aged 65–69 years.[112,113]

"Age Concern is disappointed and believes the government's proposal to set up two small pilot projects is an unnecessary delay, since major research trials from abroad already confirm that substantial numbers of deaths can be prevented by screening women up to and beyond the age of 69. The charity has also called on the government to, at the very least, implement a public education programme to publicise the benefits of screening to women of all ages over 50, so that those who are currently not invited are encouraged to request a screening".[114]

Reviewers' commentary

Some researchers have responded to consumer action with a positive attitude towards consumer influence, either seeking consumer views indirectly through records of their individual or group action, or by conducting research on topics suggested by consumers. However, without engaging directly with the consumers themselves, they have limited understanding about consumers' views.

On some occasions consumers interpret research conducted without their input as an unhelpful sop to their demands: research called for by consumers has been delayed, and other research has been conducted in preference to meeting consumers' other demands.

Key messages

Consumer views have:

- Inspired new research when consumers wrote in their own words but in a medium that would reach researchers.[96,101,102]

- Profoundly influenced researchers' attitudes and the direction of their research when offered as a poignant message with emotive language.[96]

- Provoked bad publicity for authorities where consumers perceived them delaying research that would meet consumer demands, or conducting research as a delaying tactic.[107,115]
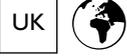
- Attracted attention to conflicts – campaigns against cloning research, animal experimentation.[97,99]

Details of Type G approaches are given in *Table 7*.

TABLE 7 *Type G Responding to consumer action with research*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
G.1 Provoking research about patients' views							
Daugherty *et al.*, 1997[96]	Clinical cancer department	Patient	Patient's essay		Changed attitudes in associated research project	Personal influence due to patient's knowledge, motivation, intelligence and comprehension	Description by participant researchers/ managers
Butler and Wadman, 1997[97]	Cloning	Public opinion	Media attention	Bioethics	Led to US- and EU-commissioned reviews on the ethics of cloning research	Wide readership but no direct engagement	Description by journalist
Aldous *et al.*, 1999;[98] Balls, 1999[99]	Cloning	Public opinion	Public opinion poll	Bioethics	Controversy and publicity	Lack of clarification about public priorities	Description by participant researcher/ manager and critique by researcher
G.2 Research matching consumers' priorities							
Colquhoun and Bunda, 1995;[100] Stevens *et al.*, 1995[102]	Clinical research: hyperactivity	Mothers of hyperactive children	Consumer-led research published in journal	Social action	Consumer research and subsequent professional research	Consumer control and adapting their communication style to suit professional literature. No direct communication. Research topics directly linked to individual consumer concerns. Topic expressed in consumers' own words and a research framework. Impact on research fortuitous	Description by participant researchers/ managers; and by participant consumers
Newburn, 1990;[103] MacArthur, 1990;[104] Kitzinger, 1987;[105] National Research Register, 2001[106]		National consumer group	Letter in medical journal	Social action	Consumer priority on national research agenda and commissioned research project	Wide readership but no direct engagement	Letter by participant consumers

TABLE 7 *Type G Responding to consumer action with research (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
McCoy *et al.*, 1992;[107] Gibbs, 1982[108]	State Department of Health and Rehabilitative Services	Women in the local community	Lobbying	Social action	Epidemiological study		Description by independent researchers
G.3 Research contradicting consumers' priorities							
Age Concern England, 1996;[109] Hendry and Entwistle, 1996[110] Horton Taylor *et al.*, 1996;[111] Age Concern England, 1995[113] and undated; [112] Age Concern England, undated[114] Age Concern England,1995[115]	UK Department of Health	Age Concern	Lobbying	Social action	Controversy and publicity		Reports by consumer participants

Type H: independent consumer action

Where consumers acted independently in identifying or prioritising research topics, we designated it as Type H engagement (with research, rather than researchers or research programmes) (*Figure 10*). In searching for consumer involvement in setting research agendas, we found examples of consumers calling for specific research where we found no evidence of this call being heeded. Consumers sometimes placed their calls for research in the national press or the scientific press, and sometimes their actions were recorded by journalists or researchers. We have not addressed the many examples of consumers prioritising and conducting their own research.

Summaries of all the reports based on authors' original descriptions of the processes and outputs of individual examples for each forum appear below. These are followed by our own comments as reviewers on these methods and, finally, key messages that we have deduced from reviewing Type H approaches to consumer involvement.

Unheeded calls for research?
- We found a call for controlled trials on multiple sclerosis.[116] It was supported by in-depth knowledge of the subject and an understanding of research design.

- An article from a consumer group in the scientific press invited researchers to join HIV activists in debating whether and how AIDS vaccine research should be conducted.[117]
- Research priorities held by parents of autistic children did not match research priorities of professionals, and a closer relationship between the consumer group Autism Society of America and the NIH would be required if their priorities were to be met.[118]
- The Consumer Federation of America conducted its own national survey on a variety of consumer issues, in which questions about indoor air quality were raised. This led to a well-resourced campaign for the Federal Government to conduct additional research on air pollution.[119] We found no record of a government response.
- The National Depressive and Manic Depressive Association of America is a network of self-help groups. It convened a consensus conference that addressed six key questions, including issues about the gap between our knowledge of the diagnosis and treatment of depression and actual treatment received. The target audience included health policy makers, clinicians, patients and their families and the public at large. The consensus statement included a call for conducting research on development and testing of new treatments for depression.[120]

| | | Consumers' degree of engagement | | | |
		Consumer Control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A	Type B	
	Inviting individual consumers		Type C	Type D	
	Responding to consumer action		Type E	Type F	Type G
	Minor partner or absent	Type H			

Type H: consumer calls for research; consumer-conducted research

FIGURE 10 *Framework for describing Type H consumer involvement in research agenda setting: independent consumer action*

Reviewers' commentary

Consumers have sometimes taken the initiative to construct their own research agenda, whether or not they have identified research programmes that may have the remit to adopt and commission such research. Their calls for research have been supported by resources, organisation and well-informed, sophisticated argument. Sometimes consumers invited professionals to collaborate.

Consumers' own research

We have not included here the vast literature of consumer-led research. However, two of the UK programmes that we investigated with interviews and document analysis included examples of consumer-led research: the Mental Health Foundation and the NCT (see the next chapter).

Key messages

The key message is as follows:

- Consumers call for research and conduct research in many different areas. This probably provides a rich and largely untapped pool of research topics.[117–121]

- Consumer activism that has had a profound effect on health policy and services has not had the same impact on research agendas in the UK that has been seen abroad.[10,82–86]

Details of Type H approaches are given in *Table 8*.

TABLE 8 *Type H Independent consumer action*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
H.1 Consumer calls for research							
Hanson, 1992[116]		National consumer group		Social action	Consumer-identified research topic – national press publicity	Wide readership but no direct engagement	Article by participant consumer
Harrington, 1992[117]		HIV/AIDS consumer group		Social action	Consumer-identified research topic – scientific press publicity		
Schopler, 1996[118]		National consumer group		Social action	Comparison of consumer group priorities with national research programme		
Fise, 1992[119]		National consumer federation		Social action	Consumer-identified research topic – press publicity		Reported by participant consumer
Hirschfield *et al.*, 1997[120]		Consumer groups and members of the public	Consensus conference	Social action	Identified research priorities	Consumer-led consensus conference with professionals	
H.2 Consumer-controlled research							
The Mental health Foundation, 2000[129] *Case investigated in more depth for UK episodes (see Chapter 5)*	*Mental Health Foundation*	*Service users and those who have suffered mental distress*	*Survey*	*Empowerment Equal opportunities*	*3 research topics identified and prioritised*	*Broad involvement of consumers*	*Report by participant researcher/ manager who was also a consumer, and interview*

TABLE 8 *Type H Independent consumer action (cont'd)*

Authors(s)	Research programme	Consumer group(s)	Method of interaction	Theory of interaction	Output of interaction	Advantages/disadvantages	Nature of evidence
Oliver, 1993[42] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NCT*	*Maternity service users/NCT members*	*Written consultation, conference and meetings*	*Social action*	*15 topics and 5 priorities*	*Consumer networks facilitated consultation*	*Description by participant consumer*

Chapter 5

UK experience of consumer involvement in agenda setting

Types of interactions in the UK

The UK cases that we chose to investigate with interviews and document analysis varied widely. Some were focused primarily on the action of consumers (Mental Health Foundation, NCT and the IDDT) or charities (Alzheimer's Society, Health Action for Homeless People). Others were focused on NHS national and regional research programmes, which sought input from a range of consumers (HTA programme, Northern and Yorkshire's Older People Programme, PCD programme, Primary Dental Care programme and SDO programme).

Research focused on specific conditions (Alzheimer's disease, diabetes, pregnancy and childbirth, mental health) on populations (older people, homeless people) and services (primary dental care, service delivery and organisation). Some research organisations drew on direct experience of consumer involvement in health services and research more generally (HTA programme, Northern and Yorkshire's Older People programme).

Consumers were members of experienced campaigning groups (NCT, Mental Health Foundation), members of charities (Alzheimer's Society, Health Action for Homeless People), individual patients (primary dental care programme) or carers (Alzheimer's Society) or members of the public (primary dental care programme). Some consumers had long experience of research (NCT, Mental Health Foundation), whereas others were more often new to research (Alzheimer's Society). Some examples were consumer led (Mental Health Foundation, NCT).

Engagement was through collaboration (HTA programme, PCD programme) and consultation (SDO programme). Methods included written consultations, face-to-face consultations, committee membership and indirect methods such as scanning consumer literature, and questions to helplines and Members of Parliament.

Each case is described below. The advantages and disadvantages attributed to the different methods are presented without reference to the individual cases. We have adopted this approach to maintain the confidentiality of key informants who have willingly allowed us to learn from their failures as well as their successes.

Northern and Yorkshire R&D Directorate's older people's programme – Health and Social Care Issues for Older People

This case is described from unpublished reports and working papers,[36,122–125] and interviews with a member of the Northern and Yorkshire R&D Directorate programme staff and with two individual consumer participants from programme workshops.

Identification and prioritisation of research topics
From 1998 to 1999, Northern and Yorkshire NHS Regional R&D Directorate used a combination of methods to determine priorities for research. Questionnaires and focus groups initially identified older people as a priority area. Two workshops were convened later to identify and prioritise research questions within this area.

Approach to engagement
This is a Type A example where the research programme invited members of consumer groups to collaborate. A range of consumers was involved in each of these stages of the process. The programme worked with local individual consumers and representatives of consumer groups with little previous experience of research. The programme manager was experienced in terms of consumer involvement.

Methods of interaction
A questionnaire was distributed to consumers through a range of routes, including GP practices, nurses, midwives, health visitors and market researchers interviewing on streets. Focus groups were convened using Patient Partnership and Community Health Council networks. Older

people were identified as the first priority group for research.

Two workshops were then held in May and November 1999. The May workshop was aimed at older people, and aimed to identify broad areas for research. Health and social care professionals gave presentations, and an older person chaired the day. There were individual older people present at each workshop, invited because of their links with local healthcare groups (e.g. primary care groups), in addition to representatives of older people's organisations, such as Age Concern and the Association of Retired People over 50. Participants discussed issues in small groups and raised a number of broad issues for research.

The November workshop was aimed predominantly at researchers and health professionals, although the consumers (older people and representatives of older people's groups) from the first workshop were also invited. This workshop developed the areas identified at the May workshop into 30 research questions. A postal prioritisation exercise was subsequently sent out to workshop participants asking them to select five research questions from the 30.

One of the consumer participants, a local 'older person' sent out the final prioritisation exercise to other older people's organisations in the York region, as she felt that the exercise would benefit from a broader spectrum of older people's opinions.

Output
The five research priorities selected by the final postal exercise were:

1. What are the interventions that prevent extra disability in older people and promote health and well-being?
2. Evaluate different models of rehabilitation for their impact on health outcomes and well-being for older people.
3. What are the most effective ways of identifying and working with older people suffering from depression associated with physical illness, disability and social isolation?
4. What are the educational and training needs of staff in nursing and residential care homes and how can their profile be raised in order to promote recruitment and retention?
5. What are the definitions and indicators of quality care in nursing and residential care homes from the perspectives of residents,

potential residents, families of residents and people working in the homes?

In the call for research proposals in February 2000, these questions had been subsumed into three broader research areas. The commissioning brief also asked researchers for "recognition of the user perspective within applications".

NHS R&D Health Technology Assessment (HTA) programme
This case is described from the published report of the Advisory Group and the unpublished report of the consumer consultation,[32,126] from the programme's web pages and from interviews with one programme staff member and two consumer panel members. Four authors of this report played a role in developing consumer involvement in the HTA programme. The interviewer, who had not been involved in this way, interviewed another member of staff supporting consumer involvement in the HTA programme.

Identification and prioritisation of research topics
The HTA programme is a national programme aimed at ensuring that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and provide care in the NHS. People from all these groups have been involved in determining priorities for the programme. Widespread consultation identified up to 1500 suggestions each year. These were prioritised by expert panels, aided by short scientific summaries of possible research areas (vignettes) written by in-house NCCHTA staff with the help of experts in the field. Researchers were then commissioned, following peer review, to produce health technology assessments, which were published – again after full peer review – in the HTA monograph series.

Approach to engagement
This research programme employed Type A engagements (inviting members of consumer groups to collaborate) and Type B engagements (consulting members of consumer groups). Consumers were formally introduced into this process in 1997, and have been engaged throughout the process.

Methods for interaction
In a short action research pilot study, consumers were involved in all stages of the programme: identifying and prioritising research topics,

commissioning and reporting research and communicating openly about the programme. The programme drew on the experience of campaigning, self-help and patient representative groups, national charities, health information services, consumer researchers and journalists for various tasks. Potential consumers were identified through national consumer groups and by using informal networks and databases such as Helpbox,[127] which was a database of organisations providing patient information (more recently made available on the Internet[128]), and the NHS Users and Carers Database held by the NHS Executive office in Leeds.

Consumer literature was explored as a potential source for research questions and as a route for disseminating research findings. These innovations were complemented by training, one-to-one support and discussion. A reflective approach included interviews with consumers, co-ordinating staff, external observers and other programme contributors, document analysis and multidisciplinary discussion (including consumers) between programme contributors.

Consumer involvement became more established with a dedicated Consumer Liaison Manager post in 1998. The programme's documents assumed consumer involvement to be necessary for improving the quality of research. Job descriptions and person specifications were developed. Procedures were established for identifying consumers and inviting and supporting their involvement. Two consumers joined each prioritisation panel of 18–20 members. They were asked to call upon their consumer expertise but not to aim to represent any particular interests *per se*. When giving their expert views on research vignettes consumers were asked to comment on the importance of the research question, the tone or flavour of the vignette and changes or additional information that would be useful. Consumer referees of research proposals were particularly asked to consider the choice of outcomes, patients' views about healthcare, their needs for information and support and patients' relevant experiences in healthcare settings and everyday life.

Feedback was invited from consumers and those working with them. Key developments in response to this feedback included establishing a mentor scheme for new consumer panel members, amending guidelines and forms for referees to make them more 'consumer friendly' and training NCCHTA staff to seek and support consumer expertise.

Output
When seeking research topics, face-to-face discussion with a consumer group was more productive than scanning consumer research reports. The research questions identified were:

1. How effective are primary care interventions for parents of children with mental health problems?
2. Can acupuncture relieve symptoms of schizophrenia, manic depression or acute severe depression?
3. What impact does addressing religious and spiritual needs have on mental health?

None of these were prioritised for research to be commissioned by the programme.

Where consumers were involved in refining short scientific summaries of possible research areas, they were able to make useful suggestions for how health service interventions should be evaluated: the outcomes against which they should be assessed (e.g. social and emotional outcomes in addition to clinical measures), the implications of the context of the evaluations (e.g. patients' relationships with their carers), the impact of evaluation on patients (e.g. how data collection methods relate to support during care) and the information and support that patients would need if they are involved in such evaluations. However, it remains to be seen whether these suggestions were retained as far as the commissioned research.

Where consumers were involved as members of prioritisation panels, no records were kept of consumers' priorities or how they influenced the research topics that resulted from the prioritisation process.

Mental Health Foundation's Strategies for Living programme
This case is described from a published research report,[129] and an interview with a Strategies for Living project worker.

Identification and prioritisation of research topics
The Strategies for Living Programme was funded by the National Lottery Charities Board for 3 years, between 1997 and 2000. A final report has now been produced. Consultation took place with a range of users for topic identification and research design. A previous survey of mental health service users, undertaken by the Mental Health Foundation, 'Knowing Our Own Minds', identified three main areas requiring further in-

depth investigation. These areas, talking treatments, religious and spiritual beliefs and complementary therapies, were taken as the starting points for the Strategies for Living qualitative study, for which mental health service users were interviewed. A 'user consultant' then did a preliminary piece of work, visiting 15 user groups across the UK to develop user networks and gauge user views on the topics and focus of the programme. A user advisory committee was set up for the project, with regional and national user groups and voluntary organisations, such as the Asian Mental Health Project, Manchester, and the Depression Alliance and Manic Depression Fellowship.

Approach to engagement
This is an example of a Type H engagement where a consumer group has control of setting the research agenda for its own research. This Mental Health Foundation project was a 3-year national, voluntary sector research project. The project's work with mental health service users illustrates an empowerment model based on user-led research.

Methods for interaction
The programme incorporated user involvement throughout the project, from directing the project as a whole to identifying topics and designing, undertaking and disseminating the research. Consumers involved in the project were defined as individual current or past mental health service users "or those who have suffered mental distress". This included Mental Health Foundation project staff, representatives of a range of user groups on the advisory committee, and interviewers and researchers employed on the project. The project strove to "uphold principles of empowerment, consultation, involvement and equal opportunities".

Output
The programme incorporated different strands or themes, including a qualitative research study, a research support network with six user-led projects and dissemination. This programme of work has since been published as a book giving an account of the development and implementation of innovative projects in user-led research[130] and five individual project reports about the role of mosques, acupuncture, massage, drop-in centres and user groups for people with mental health problems.

National Childbirth Trust (NCT)
This case is described from the text of a conference presentation and internal consumer group working papers.[42] The consumer member of the NHS Mother and Child Health programme sub-panel was unavailable for interview.

Identification and prioritisation of research topics
The NCT is a national voluntary membership organisation with considerable experience of participating in research. The NCT was founded over 40 years ago. It aimed to enable every parent to make informed choices through campaigning and offering information and support in pregnancy, childbirth and early parenthood. It has over 250 branches across the UK, operated largely through the work of trained volunteers, and has funded and led research projects to inform its work. The NCT has its own Research and Information Group and has developed working relationships with the NHS research community. Research priorities were set by discussion within the Research and Information Group and by consulting the wider membership. This description focuses on this exercise and on the NCT's subsequent submissions to national research programmes within the NHS.

Approach to engagement
This example is of a user-controlled agenda setting exercise (Type H engagement) where the findings were subsequently used in response to research programmes' consultations of consumer groups (Type B engagement).

Methods for interaction
Formal processes for setting research priorities attracted increasing attention in the UK with the launch of the NHS R&D strategy in 1991. In response to an invitation, the NCT submitted eight principles to the Strategy for Nursing, Midwifery, and Health Visiting Research in 1992.[131] A year later, another invitation to the NCT to present 'consumers views of midwifery research' at a midwives' study day prompted the organisation to set its own research priorities. Several articles about research featured in an issue of the organisation's quarterly journal. The profile of research was raised at the annual national conference and leaflets were circulated to all NCT branches asking members what research they would like to see conducted. To generate ideas, members got together locally and held discussions in committee meetings, at social events and training sessions and in branch newsletters. Responses were received from over 15 branches who had held discussion groups on the subject, from five individuals and from members of the Research and Information Group. Topics were

then collated by the chairman of the Research and Information Group, resulting in a list of 15 topics. These topics were then scored by a panel of 10 NCT members. The list and scores were circulated on a smaller scale to the Research and Information Group, the Trustees of the NCT and four NCT branch members with no special interest in research to prioritise five topics.

The NCT drew on this exercise in order to respond to written consultations from NHS R&D programmes: Mother and Child Health; Primary/Secondary Care Interface; and the HTA programme. The NCT also responded to a survey by the National Perinatal Epidemiology Unit (NPEU) (a research centre funded by the Department of Health to improve the health and well-being of women and their babies during pregnancy, delivery and after birth).

Output

The NCT made four recommendations to the NHS R&D programme on the primary/secondary care interface. The first was that the primary/secondary care interface should not pose a barrier to long-term outcome measures. Topics for evaluation were counselling skills to allow women informed choice; caring for carers; and evaluation of all named midwife schemes. Ultimately, the programme addressed 20 research priority areas, the 11th of which was patients' and carers' social needs. Evaluations of a patient information programme and a carer support programme were commissioned, but neither of these was in maternity care.

Twenty-one research topics were recommended to the HTA programme: the value of full information and support in pregnancy, during labour and following birth; effectiveness of antenatal education; ultrasound during pregnancy; treatment of women with high blood pressure at home; eating and drinking in labour; high intervention rates during childbirth; inducing labour after term; epidural anaesthesia for labour; 'mobile' epidurals; scalp clips for electronic fetal monitoring in labour; delivery of breech babies; giving birth in water; prevention of postnatal infections; repairing the perineum; bili-blankets for phototherapy of jaundice in newborn babies; postnatal exercise; counselling and advisory role of health visitors; support for postnatal depression; named midwife schemes; developmental screening for young children; and immunisations. One of these, a systematic review of ultrasound screening in pregnancy was subsequently commissioned by the HTA programme. Other topics were

commissioned by the Mother and Child Health programme: epidural anaesthesia, 'mobile' epidural anaesthesia and support programmes for postnatal depression.

Five priority areas were recommended to the NPEU. These were methods for effective communication and support to meet individual needs; methods for preserving an intact perineum; attitudes of midwives to breast feeding rates of mothers; current practice in midwifery training on breastfeeding; and withholding food and drink in labour. These were also submitted to the programme on Mother and Child Health. The NPEU study of consumers' priorities was not published. None of the NCT's top five priorities appeared as priorities or commissioned research projects in the Mother and Child Health programme.

Health Education Authority's Expert Working Group on Homelessness

This case was described from the published report of the working group and interviews with two members of the group.[24]

Identification and prioritisation of research topics

This group was part of a wider HEA strategy, which set up 10 expert working groups to look at the potential for health promotion with vulnerable population groups. The working group was asked to produce a research agenda based around five questions:

1. Which health interventions, if any, work to promote the health and well-being of individuals, families and communities, and to prevent ill health?
2. How well do they work?
3. Do they currently contribute to a reduction in inequalities in health?
4. What are the principal health promotion needs of these groups?
5. What are the implications for new research, development and policy agendas?

A literature review was circulated to members before the group met. Members were asked to add to this and prioritise issues. The aim was to achieve a 'broad-based agenda'. The expert working group met over 2 days. The first day involved discussion of the issues each member felt should be included in the research agenda. Each member was asked to prepare a position paper addressing the above questions and did a short presentation to the group on topics they had

identified. The second day involved analysing gaps in the research agenda and further defining and prioritising issues. A report was produced from the day. Each member was asked to comment and further position papers were drawn up. The homelessness agenda setting expert group was allocated a budget of £12,000.

Approach to engagement
This is an example of a research programme inviting members of a consumer group to collaborate (Type A engagement) in setting the research agenda through committee membership. Representatives of two organisations representing homeless people were involved in identifying and prioritising issues for research on the HEA's expert working group, which produced the report, 'Promoting the health of homeless people, setting the research agenda'.

Methods for interaction
The Health Education Authority's expert working group included 11 members, comprising academics, practitioners and representatives (members of staff) from two homeless organisations, Health Action for Homeless People and Homeless Alliance. Health Action for Homeless People is a regional grant-funded voluntary group that works on health and homelessness issues in London, carries out policy development and provides information, research, seminars and training. It encourages participation and involvement of homeless people in developing services. The Homeless Alliance is an umbrella group for homeless organisations.

Output
The five priority areas identified were housing and health, service provision, health promotion needs, approaches of health promotion and social policy and development programmes. Health Action for Homeless People went on to do a subsequent piece of work, which involved two pilot exercises, one on the resettlement of homeless people. This involved talking to homeless people about how they saw their health. The Chair of the group also set up further research work with vendors of a weekly magazine produced and distributed by homeless people, the *Big Issue*. This research was about peer education in disseminating health promotion issues, in which the users (*Big Issue* vendors) were involved in the research design.

NHS R&D Physical and Complex Disabilities (PCD) programme
This case was described from the unpublished report of methods of working, a previous study of consumer involvement in the NHS R&D programme,[55] and interviews with a non-consumer member of the programme's advisory group and the consumer member of the programme's advisory group.

Identification and prioritisation of research topics
The priority setting phase of this national NHS programme of commissioned research took place over a period of 7 months from November 1992.[55] It was directed, like all the other so-called 'time-limited' NHS programmes, by an advisory group.

Approach to engagement
This is an example of a research programme collaborating with members of a consumer group (Type A engagement) and consulting members of consumer groups (Type B engagement). This was the second national time-limited NHS R&D programme (after Mental Health) but the first to have a consumer representative as an advisory group member. This consumer was a representative of The Society for Research in Rehabilitation (RADAR), a national disability organisation.

To identify topic areas for the programme, consumer groups, along with other organisations nation-wide, were targeted by a written consultation. Regional workshops were held to gauge the regional concerns and needs of users and carers. The programme's advisory group had a consumer member. In addition to helping direct the programme, the advisory group members identified and prioritised the research areas identified through the written consultation and workshops.

Methods for interaction
The programme identified areas for research through a written consultation that targeted national groups;[140] organisations were consulted. Consumer groups included the Alzheimers Disease Society, the College of Health, MIND and the National Consumer Council. RADAR also worked with the programme to convene a set of regional workshops to identify regional R&D needs. These workshops involved individual service users and carers, in addition to health professionals and researchers. The advisory group prioritised the areas raised through written consultation and regional workshops.

Output
There were no separate records of consumer priorities. The 11 broad research priorities

included 'consumer views' and 'using carers' views to develop and evaluate new forms of support', and these were well represented in the subsequently commissioned research. Three commissioned projects gave consumers a role in service planning and evaluation: practice guidelines for primary healthcare teams to meet the needs of Asian carers' needs; evaluating service support to families with a child with sickle cell disorders or thalassaemia; and carers' perspectives on discharge procedures for young adults with physical and complex disabilities (see http://www.doh.gov.uk/research/swro/rd/national/pcd/funded/fulllist.htm).

NHS R&D Primary Dental Care programme

This case was described from the published report of the Advisory Group[45] and an interview with a programme staff member.

Identification and prioritisation of research topics

The priority-setting phase of this national NHS programme of commissioned research spread over a period of 11 months from 1993 to 1994. Like the other time-limited NHS R&D programmes, the programme was directed by an advisory group. The 260 areas were first condensed into 26 broad topic areas and justification papers were prepared for each topic area by independent reviewers, identified by the advisory group. These broad areas were then prioritised by the advisory group, with a final 20 priorities being identified, of which the top 10 were noted as the highest priority.

Approach to engagement

This is an example of a research programme inviting a member of a consumer group to collaborate (Type A) and a trawl of sources of consumer views. This advisory group had a representative from the Patients Association as a member who participated in the prioritisation of topics found through the consultation and retrospective searches.

Methods for interaction

A variety of routes were accessed in order to gain the consumer view, including indirect methods such as retrospective searches of parliamentary questions and of queries to a consumer health information line. A broad written consultation also took place and a representative of a national consumer group was a member of the prioritisation advisory group. One of the terms of reference of the programme was to gain the consumer perspective to a greater extent than in

previous similar programmes. A programme staff member explained that the reason for engaging with indirect routes was the difficulty in defining consumers of primary dental care. One indirect approach involved a retrospective search over a 3-year period of Oral Parliamentary Questions, Written Parliamentary Questions and Early Day Motions, in order to identify expressions of concern from MPs. This revealed areas of concern, such as access and availability, school dental check-ups, water fluoridation and cross-infection control in general practice.[45] The second indirect method was use of a consumer health information helpline, Healthwise on Merseyside. The R&D programme staff carried out a retrospective search of issues relating to dentistry during a 6-month period. This method also raised issues relating to access and availability of NHS dental treatment, including emergency treatment out of hours, cost and confusion amongst consumers regarding their status as NHS or private patients.[45] In addition, a written consultation targeted consumer organisations and charities, who were asked to provide priority areas of research need. The response to this was described as 'disappointing', with 40% of the organisations contacted responding, but it did reveal concerns about access to dental care for certain special needs groups and the general availability of NHS dentistry. Finally, there was a review of the evidence submitted to the Health Select Committee on Dental Services with particular interest paid to evidence submitted from the Association of Community Health Councils for England and Wales. This also raised issues around access, registration and the dividing line between NHS and private dentistry.

The programme staff had no prior experience of working with consumers but tried to build on the experience of other NHS R&D programmes. The second term of reference for this advisory group was "to develop and evaluate an approach to setting priorities … with particular reference to methods of incorporating a consumer viewpoint into the process".[45] The group was encouraged when the Patients' Association showed considerable interest and the Executive Director was subsequently invited to participate in workshops and join the advisory group. On reflection,

> "capturing the consumer view was not without difficulty. Having consulted with consumer groups nationally and locally, and having also approached the problem through examination of the parliamentary structure, there is, without doubt, more work that could be done in this area. The relevance of methodologies such as focus groups is perhaps a little

unclear when considering primary dental care, since it is difficult to clearly define a primary dental care consumer and, furthermore, there are no specialist organisations or groups who represent specifically those who use the primary dental care system."[45]

However, the four methods described above provided a consistent picture of the consumer's view and they provided a basis for future work in this area.

Output
The final priorities were phrased in terms of broad topic areas. Some of these matched consumers' priorities, including availability/accessibility of dental services (first priority), healthcare for older people (ninth priority), school screening research (11th priority), fluoridation and alternatives (16th priority) and professional interface (19th priority). In addition, the 'consumer voice' was the fourth research priority. No information about the research subsequently commissioned was available on the website in June 2001.

NHS R&D Service Delivery and Organisation (SDO) programme: National Listening Exercise
This case is described from interviews with a member of programme staff who was present at three-quarters of the events and three consumers who were involved in separate focus groups: one from a carers' organisation, one patient representative from a Primary Care Group and one member of the public.

Identification and prioritisation of research topics
The priority setting phase of this national NHS programme of commissioned research was a National Listening Exercise over a 6-month period, from October 1999 to March 2000. This specifically aimed to consult a wide range of stakeholders, "especially service users",[74] and identify broad "areas of particular concern" or themes for service delivery R&D.

Approach to engagement
This is an example of a research programme consulting members of consumer groups (Type B) and the wider public (Type D).

Methods for interaction
The programme used a focus group model combined with expert groups. Sixteen regional 'mixed stakeholder' focus groups were held around the country[74] and six expert groups met (three of research funders, two of educators and

one of consumers), with a total of 24 events. Programme managers engaged with existing regional R&D networks through R&D Directors to recruit consumers for focus groups. They included members of groups of consumers, such as patient members of Community Health Councils, Primary Care Groups and carer and other voluntary organisations, plus individual members of the public who did not have an affiliation with a specific consumer group. The consumer expert group was made up solely of 11 members of the public (users/patients/carers). The final report's description of the exercise's methods was particularly clear and made it possible to determine the proportion of consumers involved: consumer representatives, members of the public and service users made up 19% of all participants.[74]

Each focus group was a half-day or evening event led by SDO staff. The sessions included a presentation of the context of NHS R&D. Group discussions were then structured around seven key questions. Examples of the questions discussed at each session are, 'If there was one change to the organisation of NHS services which you would like to see, what would it be?', and 'Thinking 5 years ahead, what would make you say the SDO R&D programme was a great success?' Travel expenses were paid for all participants.

Output
There was no record of consumers' priorities for research. The 10 broad areas identified as a result included 'user involvement'.

CABI Bioscience's Farmers Participatory Training and Research programme
This case is described from an unpublished report, the organisation's website[66,132] and an interview with a member of the programme staff.

Identification and prioritisation of research topics
CABI Bioscience is a programme that evolved from the London-based Commonwealth Agricultural Bureaux. The original aim of supporting agricultural scientists by identifying insects and providing scientific information and technical assistance has since broadened to an international remit to tackle problems in agricultural sustainability and biological diversity. There are no methods for identifying and prioritising research topics for the Integrated Pest Management programme independent of working with farmers in developing countries, as described below.

Approach to engagement

This is an example of a research programme inviting individual consumers to collaborate (Type C). The Integrated Pest Management programme employs an action research model, where local farmers are trained through discovery-based learning to choose topics for research and then carry out their own research projects.

Methods for interaction

This programme trained farmers in developing countries to become researchers, through discovery-based learning at Farmer Field Schools. During the training process, farmers suggested topics for experimentation. Trainers/facilitators worked with farmers to find solutions to their problems. Farmers then learnt through doing their own research, generally on pest and disease management. The field was seen as 'the primary classroom'. The aim of the programme was two-fold; to bring Integrated Pest Management knowledge, which has been developed over the last 20 years but remains at the level of researchers, to the farmers, and to work with farmers so that they can develop their own skills in experimentation and research.

Farmer Field Schools were set up in local settings, generally for one season. Communities were approached and asked whether they would be interested in having a Farmer Field School. Decisions were made in partnership with the village elders, who selected the farmers to participate in the programme. The participants were smallholder farmers, who had difficulties earning enough money for their livelihoods. They had no previous experience of research, and often little background education. The overall aim was to encourage the spreading of knowledge and skills, so that those farmers trained would be able to take knowledge back to the village and train others within their communities.

The programme had a participatory ethos, with two-way communication and partnership between farmers and facilitators encouraged during the learning/research process. There was an ongoing element to such programmes, with a follow-up session the year after the Farmer Field School had taken place. The programme worked with a range of partners to fund Farmer Field Schools and developed networks between non-governmental organisations, international organisations and local governments.

Output

Farmers suggested topics for experiments in Kenya. These included 'soil pest and disease management for nursery beds, and use of milk sprays to control leaf diseases in tomato'.[66] A range of traditional methods were tested experimentally, and where conclusions were clear cut farmers subsequently adopted more methods giving better crops.

Alzheimer's Society's Quality Research in Dementia programme

This case was described from the Society's web pages and an interview with a member of staff.

Identification and prioritisation of research topics

The Alzheimer's Disease Society is a charitable organisation founded in 1979 by a consumer and subsequently led by professionals and renamed the Alzheimer's Society. It is a leading UK charity for people with Alzheimer's disease and other dementias and their families and carers and funds a research programme by responding to researchers' proposals.

Approach to engagement

The research programme was relaunched in 1999 as Quality Research in Dementia. Plans included involving consumers in setting the research agenda in partnership with professionals (Type C).

Methods for interaction

The programme literature[64] describes plans for matching its research agenda to the real needs of people with dementia and their carers.

An open invitation was put out, via the Alzheimer's Society newsletters and the Internet, to carers and people with dementia to become involved in the Society's Quality Research in Dementia programme in April 1999. A Quality Research in Dementia Advisory Network was set up, which was made up in large part of carers of people with dementia. Members of this network were then involved in agenda setting within regional workshops. The workshops included a prioritisation and training exercise, designed primarily to introduce carers to the complexities of research funding and the issues associated with prioritising the three broad streams of the Society's responsive research programme: cause, cure and care. As a training exercise, participants were provided with Monopoly money and were asked to allocate funds amongst the three areas and to discuss this.

The Society has a budget for consumer training and support and has appointed training consultants

with experience of working with consumers on research issues. Carers have been involved in a range of research activities. They have commented on research grant applications being made to the Society, helped to decide which research should be funded, been involved in research in their local area, commented on research that the programme is funding and helped get the results of research into practice in their local area.

Output

The consumer advisory network was asked about their priorities for research in 2001. Ideas from 150 carers and people with dementia were posted on the website as a relatively unedited list of suggestions. These included general research issues such as identifying gaps in knowledge and how they can be filled and addressing the challenge of getting research into practice. More specific ideas supported basic science to identify the causes of Alzheimer's disease, epidemiology, genetics, methods for diagnosis, clinical research including prevention and treatment and research specifically on family carers, institutional care and daily experiences and activities of people with dementia. Researchers intending to apply for research funding were advised to consult this document before submitting their proposals.

Insulin Dependent Diabetes Trust working with the Cochrane Diabetes Review Group

This case was described from the perspective of the consumer group. We were unable to interview any of the professionals involved in the group. We interviewed a consumer member of the group and drew on the IDDT Newsletter.[30]

Identification and prioritisation of research topics

The research goal of the IDDT is to try to ensure that independent, large-scale, long-term, methodologically correct research is carried out into all the reported problems with 'human' insulin so that insulin treatment is evidence based. The IDDT worked with the Cochrane Diabetes group, within the Cochrane Collaboration, whose mission is to prepare, maintain and promote the accessibility of systematic reviews of the effects of healthcare policy and practice. Its key principles for working, include "minimising bias through … ensuring broad participation; striving for relevance by promoting the assessment of interventions using outcomes that matter to people; [and] enabling wide participation … by reducing barriers to contributing and by encouraging diversity". These principles encapsulate consumer involvement. However,

another key working principle of building on enthusiasm presents a barrier to formal agenda setting. How topics for research were prioritised varied between review groups. In most cases it was through responding to the enthusiasm of volunteers to undertake systematic reviews.

Approach to engagement

The approach of the Cochrane Collaboration as a whole can be described as Type A and Type B approaches to engagement, as there is an open invitation to collaborate, which includes individual consumers and members of consumer groups. Within individual Review Groups, the collaboration may be at the instigation of the Group, with a personal invitation to an individual consumer or consumer group, or it may be at the instigation of the consumer who volunteers their services to the Group.

The IDDT is a small national self-help group run by parents and people with diabetes. It aims to provide care and support to people with diabetes and their carers and, in the longer term, promote research into human insulin and its effects. This group had a consumer representative on the Cochrane Diabetes Review Group for 3 years from 1996. The consumer representative was a member of the IDDT, had previous experience of contributing to research agendas and was actively involved in trying to get topics on to the review agenda within this group.

Methods for interaction

The IDDT consumer member was involved, alongside professional members, in identifying topics for systematic review within the Cochrane Diabetes Review Group. The consumer representative consulted IDDT members and put forward 12 topics for review in 1997. These 12 topics included a "review of actions and effects of all available insulins", an issue of particular importance to the IDDT.[30]

Output

None of these proposed topics was taken on by the Review Group. The Review Group was disbanded in 1999.

Consumer and researcher experiences: some individual reflections

How consumers and researchers perceived these agenda-setting exercises is described below from

interview data, and an analysis of barriers and facilitators and advantages and disadvantages follows. Their views are presented first in chronological order: engaging with consumers, convening a forum, identifying topics, prioritising topics and consumers having an impact on the agenda. These views are then recast in the following section to identify advantages and disadvantages of methods for consumer involvement.

The consumer and researcher experience

Consumer involvement in agenda setting was a learning experience for consumers and researchers in all these UK cases. Within the recently established NHS R&D programme, managers often did not know what to do. Every step in engaging with people and providing a forum for the tasks of identifying and prioritising research topics was new, both with and without consumers. Later programmes found that "it made an enormous difference being able to benefit from conceptual developments in all other [NHS R&D] priority setting groups – avoided an awful lot of mistakes". The need to learn from the process was integrated into the terms of reference in later R&D Advisory Groups.

Being part of a programme that was developing and learning felt daunting for one consumer, despite her extensive experience in related areas. She felt that she would carry some responsibility if the programme was a failure, and sceptics would consider their views justified. She appreciated the support from other professionals and considered this particularly valuable where consumers might struggle with technical terms and procedures. She also acknowledged the learning within the programme management and valued the purposeful attempts to elicit feedback and respond appropriately.

Talking to people who had experience of research agenda setting was particularly helpful for programme managers outside and inside the NHS, as was experience of working with consumers in other research settings and talking to consumers through their own networks. One programme manager found her prior experience in disability research and working with consumers particularly helpful.

One consumer interpreted the tendency to exclude consumers not as deliberate but as a consequence of a "total lack of comprehension of the whole nature of the process". She raised the commonly held view that consumers are biased and asserted that everyone, not only consumers, is biased – each with their own agenda. She also rejected the assumption that the need for training is often focused on consumers' needs for dealing with issues and participating in research groups. Instead, she believed that professionals needed to learn to value other people's views and recognise that people outside the medical profession were capable of expressing valid views. Indeed, in another programme, induction training was provided for consumers, clinicians and researchers together. This was described as very helpful, but needed to be complemented by accumulated direct experience. Elsewhere, contact was limited to a one-off event and consumers were given no feedback on their contributions or the progress of the programme.

One research manager described the different responses to working with consumers. It could be "refreshing on a personal level, but some staff found it more difficult … [managers] need to move into a more supportive role, take seriously the concerns of consumers … also need to encourage, support and inspire confidence in people".

Engaging with consumers

Programme managers and consumers described the importance and difficulties encountered in the initial engagement. This was portrayed as "crossing the barriers between researchers and consumers" and it required being able to "explain what research is, what it can and cannot do, and persuading consumers that their views are important and will be acted on".

Identifying appropriate consumers to engage with was difficult. Approaching individuals or groups raised different issues. Finding individuals to suit the task could be difficult. Managers found groups easier to identify, but some consumers were disappointed when they saw people not personally affected by a condition speaking for people who were. "Someone living with the condition" was distinguished from paid members of staff "who have their own agenda – a job to keep". When managers had found consumers helpful, with hindsight they would have liked to have involved more of them, but they had sometimes limited involvement by purposely avoiding 'competing' consumer groups.

After identifying appropriate types of consumers, recruiting individuals raised other difficulties for managers. This involved, for example, explaining

the task and conditions, and securing funding or, more often, persuading consumers to work without it. 'Cold calling' was difficult. It required talking about the purpose and structure of a research programme to people who had never heard of it. Some managers approached consumers they had met in other settings, or through consumer networks with which they were familiar, and invited their participation without explaining clearly their role in advance. These consumers "struggled to know what to contribute" and "didn't feel able to key into [the programme's] objectives". They would have liked more information in advance, and if one of them "had known what it would entail [he] wouldn't have gone". These difficulties were not mentioned by those involved in episodes where consumer groups had involved consumers in their own research programmes or research agenda-setting exercises. In two very different cases (national and local), choosing the appropriate individuals was left to the consumers themselves, after they had been given a set of desirable characteristics and restrictions.

Convening a forum

The UK cases included a variety of forums: committees, workshops, written consultations, informal meetings and training events. Although written consultations were routine within the NHS R&D programme for identifying research topics, they were barely mentioned by research programme managers, and the consumers we interviewed had not participated in them. The one exception was a consumer member of a committee who had the task of sorting the responses to the written consultation, although no further comment was made.

Several consumers reported committee membership as a challenging experience. Typically there were only one or two consumer members on a committee. This was considered difficult but not unusual. Even when 'civil servants' were perceived as very supportive and willing to listen, a consumer could feel like a 'lone voice' in an area that could be difficult to understand. Despite this consumer seeing herself as having relevant research experience and able to have an influence, being the token consumer member of a group was "not a very pleasant experience … and less effective". Another experienced consumer said that she "felt out of her depth when attending the meeting – not with the content – but with the general way of working and understanding how the committees fit into the bigger framework of the R&D programme… . The first time it felt very

strange. There was a very set way of working…. At the second meeting it was much easier … I knew the process."

The role of the Chair was mentioned as an important influence on the profile of consumers in committee meetings, as were the minutes of the meeting. One consumer noted that although other committee members were named in the minutes when they made specific comments, she was not named alongside her suggestions; rather, the minutes recorded that the suggestion "was discussed". Such subtleties were seen as undermining and undervaluing consumers' contributions.

Another consumer committee member "felt it was a struggle … that [she] had to push to get views on board … [she] felt that as a representative of a voluntary organisation, she was marginalised amongst the group of academics who were 'all mates', and was made to feel an outsider". Despite the difficulties, she felt the Chair handled the situation well and her concerns were taken on board.

Committee procedures could be 'fast and furious', although consumers found it easier when attending for a second time. Supportive comments from other committee members helped. Less formal meetings could also be challenging. There were feelings of being isolated and needing to be "courageous to speak up among people who were leaders in their field". If there had been two consumers, even though still not considered enough "at least they could have offered each other support".

Consumers expressed only difficulties rather than competence or achievements when speaking about one-off events. Unlike committee members, they had no opportunity to learn from their experience and cope better a second time.

Involving consumers indirectly successfully identified topics, but was not suitable for prioritisation where there was no opportunity for discussing and refining topics.

Identifying topics

Consumers were not always involved directly in topics. Rather, consumer representatives inferred their views from their experience of talking to consumers in other settings.

Sometimes consumers found that their interests did not fit the expectations of the programme.

Topics did not always appear to be of interest. Broad topics rather than specific research questions were seen as more appropriate in one programme, although the reverse was required in another.

Identifying research topics in a workshop setting was difficult. People found it difficult to get beyond discussing a problem to expressing a productive idea. They "had lots of ideas about how health services could be improved, but found writing research questions difficult". Some managers designed questions to engage non-researchers, piloting and amending them appropriately.

Prioritising topics

Sometimes consumers were not involved in prioritising topics at all. When they were, they found it challenging.

Consumers found prioritising as part of a group discussion difficult. In one instance, when asked to combine similar topics under a single heading, "people were quite determined that whatever point they were concerned with was kept. They didn't want to relinquish their own issues".

Consumers found influencing discussions difficult. One consumer described herself as "harping on about a few things I wanted to get across about qualitative research, user involvement in research and complementary therapies".

Scientific evidence appeared to be given more weight than consumers' views, and consumers' perspectives often being presented anecdotally was problematic. In time, one consumer perceived "a gradual shift". She found her questions tended to be about qualitative issues that were less easy to measure, and that suggestions for such topics were not well received.

There was occasional cynicism about the prioritising of topics, a feeling that "whoever was in charge of the programme had their own ideas to start with. Perhaps they were concerned (not deliberately) that the spirit of their own ideas [should be] incorporated into the final topic suggestions".

Impact

The impact of consumer involvement in the research agendas was unclear. One consumer felt that consumer involvement would happen gradually. The pressure for new research agendas is not coming only from consumers. Consumers and professionals are calling for a wider, more holistic, context-based social research agenda.

One manager saw consumer involvement as potentially having a great impact on the professional research community. Because traditionally "people learn more and more about less and less, to some extent consumer involvement puts a brake on this. People would have to stop and think about the impact on the NHS patient…. If you can't convince users who are involved in the development of the programme, should that be what you are investing time and resources into researching?"

When consumer organisations involved their own consumer members, they felt it made a difference to the research topics.

Consumers could be impressed by efforts to involve them. "If that's the start of things to come, it can only be good news…. Now that people realise there's a chance to become involved more personally and directly, I think there will be a lot more people taking the opportunity."

Advantages and disadvantages seen in the UK

Circumstances or activities that appeared to disadvantage consumer involvement were identified from interview notes and programme documents by the authors of this review. These are addressed as 'barriers' below. Circumstances that appeared to be particularly advantageous for involving consumers in agenda setting were similarly identified and reported as facilitators. The outcomes of UK interactions were identified as their ensuing advantages and disadvantages. The reviewers' conclusions about barriers, facilitators, advantages and disadvantages are all presented below, but without reference to specific research programmes described above in order to maintain confidentiality of the key informants.

Barriers
Poor representation
Consumers were concerned about the poor representation in several of the UK examples. Some consumers would like to see more individuals involved in workshops in addition to representatives from consumer organisations. In committees consumers were often a very small minority, sometimes acting alone. Where committees included a range of academic disciplines, there was "only room for one consumer" rather than

justification for a range of consumers. In such situations they received complaints from other consumer organisations that had been excluded. One consumer also commented on the weighting towards academics where they would have preferred more service providers. One consumer had "felt like a lone voice" and thought consumers would be more confident and "have a greater impact" on the priority setting process if more consumers were recruited.

Sometimes consumers were unclear as to whether they should be expressing their own views or those of a further consumer constituency.

Participation rates in some written consultations were disappointing and programmes have little experience of approaching hard-to-reach groups.

Unfamiliarity
Unfamiliarity, whether with agenda-setting tasks or the people with whom they were to work, was a recurrent theme with consumers. Initially, consumers were unsure of what agenda setting was, but understood more clearly as the work progressed. They had to adapt very quickly to procedures that were well established. Consumers were easily able to identify problems that needed addressing, but found it challenging to move on to developing research questions. Observant staff could identify from consumer responses a need for further training. More experience would solve some problems, but not when consumers were involved in single events, not to be repeated.

Even consumers with a "broad working knowledge of NHS services" could find some discussions overly technical and that it was difficult to contribute effectively. Training for consumers was not always the suggested solution: consumers also called for training and changing attitudes amongst the professionals.

Unfamiliarity of researchers with consumer-centred approaches was also an issue. Researchers sometimes saw consumer views as additional information to be considered alongside research, rather than as a starting point for framing research questions. Some people found it difficult to adapt research to the needs of consumers.

Working relationships
Consumers could feel isolated. Even when made to feel very welcome, they could still feel like an outsider during discussions. Despite good group facilitation, a consumer could still feel different amongst a "group of academics" who were perceived

as "all mates". In such circumstances, it felt a struggle to get consumer perspectives on board.

Attitudes
A committee atmosphere was not always wholly supportive, and a consumer perceived an imbalance in their status with professionals. Although attitudes appeared to be gradually changing, consumers thought professionals regarded their own views as having more intrinsic value than those of consumers. This was perceived in subtle ways, such as was mentioned above when consumer suggestions were not being recorded in the meeting minutes with a name, compared with professionals' suggestions, which were. Consumers perceived some programme staff and professional participants as finding working with consumers difficult, as having a "different mind set". A contrasting attitude would be staff adopting a more supportive role for consumers and taking their concerns more seriously. In one programme, professionals trained alongside consumers. In another, a consumer thought they should do so in order to learn to value others' views. This issue was raised by staff in another programme where the need to train professionals how to interact with consumers had not been resolved.

Conversely, some staff reported consumers being resistant to their approach, saying "you are the expert, you tell us the answer". Elsewhere staff considered, with hindsight, that consumers wanted to be involved in identifying broad areas rather than dealing with specific research questions, involved in the "nitty gritty" as "research groupies". They thought consumers wanted to be involved only at the initial stages of a research programme and then again when selecting which research bids to fund. This conclusion was contradicted by cynical views of consumers (see p. 88). Consumers were critical about time constraints, lack of advance information and feedback and poor communication at meetings, and expressed a need for developing working relationships for effective consumer involvement.

Elsewhere, programme staff expressed concern about the difficulties of trying to empower and protect consumers who are often very busy dealing with illness. Consumers did not express a need for such protection.

Time constraints
Lack of time was a recurrent theme. Two-hour focus groups or workshops were considered fairly limited for discussing the range of issues involved. It could be difficult to find common ground within

a workshop session, so final decisions about research priorities were rushed.

As highlighted above, committee meetings could be "fast and furious" with time-constraining discussion. In addition, there were tight deadlines for completing work outside of meetings, which should have been agreed in advance.

Concern was also expressed about the lack of notice given prior to an event, which possibly precluded carers who needed to find alternative care in advance. Time constraints precluded the involvement of consumers who needed more support because of their personal health problems.

Lack of time presented difficulties for considering research needs across a broad area. When time was limited, some participants would have preferred to have selected more specific research areas and set priorities within these. Sometimes it was the consumer perspective that was not considered in much depth.

Programme staff could be caught between criticisms of slow progress and the time they felt was required to establish a two-way communication and learning process with consumers.

Communication
Consumers found some advance information insufficient or too general, and were disappointed by lack of feedback. Staff for this programme said they would have liked time to brief all consumers individually, but that this had not been possible. In contrast, this did happen for consumers involved in a parallel programme. Language, or more specifically jargon which could be perceived as a "foreign language", presented a barrier to participation. Consumers met concepts and acronyms in wide consultation meetings that would probably not be accessible to the "average person in the street" and said that the exercises could have been more open and accessible. Elsewhere, programme staff made specific efforts to use plain language or explain technical terms.

Facilitators
Leadership
Commitment to consumer involvement was evident where staff expressed appreciation of the support for involving consumers from their programme director. In committees, the facilitative role of committee Chairs was seen as key and their participation in less formal but supportive training activities was highly valued. Consumers were also seen in leading positions, such as chairing

workshops or leading their own work. This was viewed positively by professional colleagues and consumers.

Breadth of involvement
Broad involvement was achieved via disseminating questionnaires through a wide variety of routes within the NHS and more broadly by market researchers identifying a broad range of consumers (patients, carers, representatives and the wider public), recruiting consumers through their networks and inviting them to meetings, travelling around the country as necessary, and combining a range of methods to involve consumers at different stages in the process.

Working relationships
Some interactions could build on established working relationships, especially where there is a long history of consumer involvement. Face-to-face meetings helped working relationships develop. Consumers identified the interactions with other participants before, during and after workshops as very important, as were the information received in advance, the social aspects of a lunchtime meal and a letter of thanks and payment of expenses.

Programme staff could be particularly important in developing working relationships. One emphasised the importance of "encouragement, support and inspiring confidence in people who may think they have nothing interesting or important to say". Another described how it was important to get to know "where each consumer is coming from" so as to work with them effectively. Consumers also described being helped by supportive comments from other committee members and programme staff.

When more than one consumer was involved, they were able to give each other support.

When consumers consulted more widely, they felt that people were more willing to be interviewed by consumers than researchers, especially about sensitive health issues.

Communication
Good communication was a distinct advantage for consumer involvement. Where information about events and attendees was sent in advance, and follow-up information circulated later, consumers felt better able to understand the process. Face-to-face or telephone contact was seen as important for working with consumers, rather than relying on letters or e-mail alone. Plain English, without the technical jargon, was considered essential in

written and oral communications, and where necessary, the use of languages other than English.

Training and support

Consumers appreciated the training and support provided by some programmes. These training and support programmes had a common history, evolving from the Critical Appraisal Skills programme to help make sense of research,[133] the NCT's VOICES project designed to help multidisciplinary service planning groups work together more effectively[134] and IMPACT for developing skills and confidence to influence health care decisions (http://www.phru.org.uk/~casp/impact.htm). However, training needed to complement experience: they found it was difficult to learn in the abstract, with "no hook to hang anything on", and needed to understand the programme's purpose and how their task fitted into the bigger framework of the programme. A training day convened once they had some experience, with practical exercises, was "very useful".

Programme resources

Programme staff stressed the need for sufficient resources and time to involve consumers, preferably with a budget specifically for this purpose. Some programmes developed policies for paying honoraria. National consumer groups were able to draw on their own resources to set priorities, including staff, organisation networks and funds. Time was essential for thinking and discussion.

Building on experience

Ongoing working relationships allowed consumers to develop their skills and confidence. Similarly, staff appreciated the value of their personal prior experience of working with consumers. Informed consumers were seen as particularly useful. One consumer member of an agenda setting group was described as "knowledgeable and practical". Comments about local issues from consumers who "know the needs of a particular area" were also valuable.

Where feedback was invited about consumer involvement, consumers and programme staff talked of the programme's consumer involvement in terms of it being a developing process. This development was evident in the increasing clarity about consumer involvement with the development of procedures, guidelines and job descriptions.

Advantages

Enthusiasm

Consumers with experience of collaboration expressed enthusiasm for working together. This enthusiasm led to a willingness for future collaboration and a continued practical interest in research. Enthusiasm was not an outcome of consultations.

Impact

Where setting research priorities led to a subsequent task of consumers conducting their own research, consumer impact appeared stronger. Records of consumers' priorities were available only where consumers took leading roles.

Disadvantages

Cynicism

Consumers were sometimes disappointed not only with their lack of influence, but also the lack of opportunities to influence even when formally involved. Consumers were concerned about how research topics were chosen even for consideration in priority-setting exercises. Involvement was unsatisfactory for consumers who found their perceived needs for structural changes in the NHS were not on the agenda for discussion. Particular frustration was expressed when professional agendas were able to lead discussions and advanced the process without effective participation from consumers because professionals' background knowledge of the topics was not shared with consumers in their briefing materials. "Issues went beyond requirements for end-users and focused on a lot of internal problems…. I got the impression that they had to have a few members of the public. For what I had to say, it was of no value". The charge of 'tokenism' was made when individual consumers were invited to join large committees, and when events accommodated larger numbers but discouraged effective participation.

Impact

There was little evidence of consumer involvement influencing research agendas. It was often hard to separate professional and consumer impact. In programmes where the influence of consumers' views on the final priorities was considered by participants to be strong, priorities for consumers were also priorities for professionals. Where consumers felt their views on priorities had been taken on board, there was no mechanism for recording who had influenced decisions.

Most records did not distinguish between consumers' and professionals' priorities. Where they did, consumer priorities did not often lead to commissioned research.

Chapter 6
Synthesis of findings

The analysis of examples of consumer involvement employing similar approaches to engagement (Types A–H) suggested advantages and disadvantages associated with these different approaches. The analysis of UK cases suggested common themes to be addressed when supporting consumer involvement in research agenda setting. Neither of these analyses compared different approaches or addressed in depth the complexities of multilevel methods that combine a range of approaches to engagement, different forums for interaction and methods for exchanging ideas and setting priorities.

Questions remain about the implications of choosing particular methods. What are the advantages or disadvantages of:

- Involving particular consumers (individuals or organised groups, with specific or general interests)?
- Involving them in consultations or collaboration, in different forums, or guided by different philosophical approaches (such as organisational change or participatory research)?
- Research programmes extending an invitation to consumers rather than waiting to respond to consumer action?
- Do these advantages and disadvantages vary with the context, such as the type of research, or the organisational or geographical setting of the research or the consumers?
- How strong is the evidence supporting the findings?
- Which methods have contributed most to our knowledge about consumers' priorities for research or to developing methods for involving consumers in research agenda setting?

We attempt to answer these questions by comparing individual episodes of consumer involvement across different dimensions of consumer involvement methods and their evaluation in the following narrative synthesis, which rests on an analysis of the data presented in Chapters 4 and 5 and the data in Appendix 2.

Who was involved?

Many different methods were chosen to involve consumers in setting research agendas. Some of these involved choosing representative samples from broad populations, as in opinion surveys,[68,69] or choosing samples for the purpose of capturing views of people with personal experience of specific conditions.[72,73] Other methods involved choosing people with the skills and contacts to represent consumers' views. These included Members of Parliament asking questions on behalf of their constituents,[45] and members of organised groups who could draw on the views and knowledge of the wider group membership (Types A and B).

Only two reports compared different ways of sampling consumers in order to set research agendas.[32,45] The NHS Primary Dental Care programme[45] found that the same general broad themes of concern were consistently identified through different routes: written consultations to consumer groups, reviewing parliamentary questions and questions to telephone helplines and consumer membership of the prioritising panel. This finding diminishes concerns that self-selection of consumers, at least on this topic, distorts the research agenda. The NHS HTA programme[32] found that reviewing questions to telephone helplines identified general broad themes but that these could not be translated into research questions. Also, reviewing consumer literature identified research questions, but these were often out of date or fell outside the remit of the programme.

Generally, it seems that where efforts were made to increase inclusion by the use of large numbers, this was at the expense of depth of involvement. Where small numbers of consumers were involved, there were some concerns about 'tokenism'. Some programmes sought a middle path with consumer membership of committees combined with wider consultation,[32,34,38–40,45] sometimes conducted by the consumer committee member.[33,34,37]

Working with consumers with specialist interests encouraged informed debate, allowed consumers to consult their own networks and identified topics and priorities for research.[33,37,59] Working with established community groups was feasible, although it could be time consuming. It provided

a route for gauging local opinion from broad sections of the community, including people who were not activists and people who may be unfamiliar with the English language.[26,52,53,59,123] Working with consumers whose shared interests were not health focused faced difficulties with lack of attendance, lack of understanding and lack of commitment.[52,53] Patients recruited in clinical settings have been interviewed to identify interventions and outcomes to frame a research agenda.[72,73] Involving consumers with personal experience of problems has sometimes added an immediacy to the debate which is expressed in emotive and persuasive language.[72,75,79,96]

Who initiated the engagement?

Consumer-initiated engagement

When consumers have taken the initiative with collective social action, collaborative relationships with research programmes followed where there was a greater experience of consumer activism.[10,58,82–88,90,92,101] Formalised consumer involvement ensued on a grand scale when much of the dialogue was about the process of decision-making, as well as the decisions, in research agenda setting.[67,83–87] Well-established, politically aware consumer groups have had sufficient critical mass to provoke sustained public debate and influence the research agenda (Type F[10,95]). Less experienced activists have provoked individual studies[94,102] and influenced small programmes.[96] Activism has drawn attention to conflicts about, for instance, animal experimentation[98] and cloning research[97] and attracted publicity where consumers have perceived authorities as delaying research that would meet consumer demands, or as conducting research in a delaying tactic for other policy changes.[107,115]

Research programme-initiated engagement

Research programmes took the initiative to involve consumers in a variety of ways. When embarking on organisational change they sometimes involved consumers.[32,33,37,45–47,49,51–53,55,57,59,60] Less often their reflections considered the methods for involving consumers,[32,33,37,45,49,51–53,55,59] and more rarely still they adapted methods to support input from a greater diversity of people.[32,33,37,45,51–53,59] The greater investment in involving consumers and reflecting on the experience, the more was learnt in terms of consumer priorities and methods for involving them.

Other approaches initiated by researchers included participatory research, which either

involved individuals in specific research projects[61] or involved consumer groups in developing structures and procedures for whole research programmes.[82] Programmes involved both individuals and groups in community development or community-based health promotion initiatives.[54,70]

Consultation or collaboration?

Consumers in NHS Research has simplified Arnstein's ladder of involvement,[18] to describe degrees of involvement as consumer control, collaboration and consultation.[4] By recording the precise methods, and the influence that consumers had on research in a variety of circumstances, we confirmed a general trend that these approaches did relate to how much consumers could influence how they were involved and the influence they had on the research agenda. Within this general trend, the consumer profile prior to establishing a working relationship and the consumer profile within the working relationship also appeared to relate to the degree of influence that consumers had.

Generally, in terms of consumer influence, collaborations were more successful than consultations, consultations were more successful if consumers were consulting their peers, face-to-face consultations were more successful than written consultations and iterative interactions were more successful than one-way communication. The opportunities for individual thought, discussion and an iterative process were also linked to greater consumer influence.

Collaboration that had evolved directly from collective consumer action appeared to support greater consumer influence than collaboration that came at the invitation of research programmes. When hard won by collective consumer action (Type E), collaborations rested on changes in organisations that institutionalised consumer involvement (e.g. NIH,[67] Breast Cancer Research Program in the USA[86]), whereas research programmes could invite consumers to collaborate without making any structural allowances for their different backgrounds, thereby demanding that the consumers themselves accommodate to working together (Type A). These are the circumstances where consumer involvement may be interpreted as a token gesture to a changing political climate.

In some instances, consumers' involvement was increased by efforts to empower them in their role

within research programmes. Individual consumers invited to collaborate have included young people in poverty,[61] older people,[62] subsistence farmers[66] and people with disability[63] or dementia.[64] Although four of these episodes were predicated on theories of empowerment,[61–63,66] none of them involved a consumer in writing the report. Some of the interactions which employed team working[61–63,66] led to consumers conducting their own research.[61,62,66] This method of working was resource intensive and the identified topics and priorities were a relatively small part of the output, which included small-scale research projects completed by consumers. Elsewhere, consumers were part of a multidisciplinary research network that developed assistive technology,[63] or through face-to-face and written communication they identified or prioritised topics to be undertaken by professional researchers.[64]

Forum for exchange

Within each type of engagement, ideas were exchanged within a range of forums.

Collaborative committees, when working well, provided a structure for consumer members to introduce a broader range of views by consulting their peers.[29,33,37] Such committees needed facilitated democratic processes, openness, appropriate choice of members, support and training.[32] Consumers needed to be informed about the technical and organisational background of the work.[37] Collaborations needed to confront tensions and benefited from careful management to avoid division or breakdown in communication.[32] Individual consumers needed to be empowered to collaborate. This required investment of time, resources and personal relationships.[61–63] Collaboration within a framework of participative research provided the motivation of finding research-based answers, not just identifying the questions[32,63,66] and also provided a learning opportunity for the trainers.[62,66]

When research programmes consulted consumers, more was learnt from interactions where consumers were more directly involved in the debate, for instance through an iterative Delphi study[49] or face-to-face meetings,[32,33,37,52,53,55,58,59,66] or encouraged to participate by an independent facilitator,[58] or were even leading the debate.[37] Least was learnt from simple written consultations, either in terms of consumers' ideas and priorities

for research or about the methods used to involve them[47,48] Commercial interests that involved consumers as partners were particularly successful in capturing and making use of consumers' views, and these are considered in more depth below.[75–79]

Eliciting and prioritising ideas

Most of the reports we found were about methods of engagement. They described how consumers had been approached (proactively or reactively), which consumers had been involved (individuals or organised groups) and the media within which ideas were exchanged (e.g. focus groups, questionnaires, committee meetings). They rarely considered in detail how opinions were elicited, for instance how questions were framed or the mechanisms for expressing priorities. Nor did they report how priorities were aggregated, either the priorities of all the consumers involved or the priorities of the consumers and the health professionals. One exception was a Delphi study for eliciting research priorities for physiotherapy.[49]

A number of interactions resulting in consumer influence employed independent facilitators or consumers to lead discussions about prioritisation. It may be relevant not only who engages directly with consumers, but also specifically how they do it. We found descriptions of committees, their membership, their terms of reference and even sometimes criteria for establishing priorities. However, we found no detailed reports of how consensus was achieved in committee meetings, how they were facilitated, to what extent members participated, how voting was managed and how opinions were aggregated.

We have been able to draw on some notable exceptions, mainly from the commercial sector, where engineers have employed consensus development methods to guide their development agenda. In a two-step process, focus groups have been employed to identify development needs, followed by a broader survey to prioritise them.[76,77] Another approach was 'brainstorming' with consumers, followed by five rounds of voting.[75]

Implementation

Interviews with participants in UK examples gave us most detail about the implementation of consumer involvement in agenda setting. Vivid

descriptions of poor consumer representation, poor communication, tenuous working relationships, attitudes not wholly welcoming or supportive of consumers and serious time constraints were not limited to particular methods for involving consumers. Commitment from senior staff, broad consumer involvement, investing time and resources in meetings to develop working relationships, communication, training and support and building on experience were all seen as valuable.

Nature of the evidence

Any causal relationship inferred from this analysis is necessarily tentative largely because evidence has rarely been gathered in a systematic unbiased way. Reflections on the methods for agenda setting sometimes neglected to consider the methods for consumer involvement, and opportunities for learning and sharing were lost.[54,60] In particular, organisational change approaches to setting research agendas did not capture consumers' ideas and priorities[32,33,37,49,59] or lessons about consumer involvement[32,33,37,55] unless reflection on methods specifically addressed consumer involvement.[47,48] More was learnt about consumer priorities and methods for identifying them when programmes reflected on the methods for involving consumers.[45] Consumer involvement methods were developed further when consumers were involved as partners in reflecting on working practices.[28,29,32]

Most of the reports that we found were written by researchers or research managers who had been directly involved in working with consumers through the different types of engagement (Type A,[24,25,28,29,32,66] Type B,[32,47–49,54,55,58,59,70] Type C,[61,62,64,66] Type D,[68,69,71–73,76,77] Type E,[82,86,92] and Type G[32,45,96]). Consumers reported specific interactions where they had been invited to collaborate (Type A[33,37]), where their lobbying had led to collaboration (Type C[83–85,87,88,90]), where they had facilitated consultations[42,52,53] and where they had influenced the course of research.[100] These authors, researchers and consumers alike, were often advocates of and key players in the events they were reporting. A few reports had authors independent of the interactions, and these were written by a consumer,[31] researchers[75,79,80] or a committee with the remit of reviewing an interaction.[67]

Very few reports were of formal studies with methods sections describing the investigation of

the interaction. Exceptions were an action research study introducing consumers into the management of the NHS HTA programme,[32] a formal review by committee of the NIH research priority setting process and Health Sciences Policy Program,[67] a report of farmer participatory-training and research in traditional pest and disease management in Kenya[66] and some reviews that necessarily reviewed descriptions by authors who had participated.[35,56] The evidence is no stronger in the UK cases that we investigated in more detail. We interviewed very few people for each case. The value of these cases is in raising current issues that are particularly relevant to the UK and the NHS.

Seeking advantages and disadvantages implies a comparison with alternative methods. However, it was very seldom that we found alternative methods being compared. Exceptions included the NHS Dental Research programme, which informally concluded that the general broad themes of concern were consistently identified through different routes: written consultations to consumer groups, reviewing parliamentary questions and questions to telephone helplines and consumer membership of the prioritising panel.[45] In an engineering setting, one-to-one interviews were found to be more cost-effective than focus groups, even though identifying 90–95% of consumer needs for product development required interviews with 20–30 consumers and several analysts reading and interpreting raw transcripts.[75,79]

Much more often we are left with descriptions, often subjective, of what was good, or not so good, from which we have inferred advantages and disadvantages.

The nature of the evidence cannot support strong conclusions; rather, it demands a wary interpretation. Nevertheless, an overview of the different types of interactions reported allows us to describe the advantages and disadvantages associated with different methods previously employed for involving consumers in identifying and prioritising research topics and the circumstances in which these advantages and disadvantages have been experienced. This we do here, by considering research programmes facing different circumstances: in terms of their research focus (health topic and research methodology), organisational setting (geographical scope, leadership and funding) and assets available for consumer involvement.

Context of consumer involvement in agenda setting

Findings from this review are also tentative because of the number of potentially confounding variables that could not be clearly disentangled, particularly details of implementation, as well as contextual factors that may influence the methods for involving consumers and their subsequent influence on the research agenda. These include the focus of the research and the organisational settings of the research programme and related consumer activity.

Researchers and consumers would like to know which methods are most appropriate for different circumstances. Although particular methods have evolved in different circumstances, as we describe below, whether these may be the most appropriate setting or to what extent they are transferable to others is largely speculative.

Condition-specific research

Three topics held particularly high profiles within the review because consumer involvement here was so widespread or influential: biotechnology, assistive technology and breast cancer. The motivation and methods for consumer involvement in these areas varied, as did the outcomes. Biotechnology, including reproductive technology, appeared in three widespread consultations about contentious issues, two of which involved 10,000–15,000 participants.[68,69,95] None of these consultations were seeking ideas for research that could be readily provided by a lucrative biotechnology industry. Instead, they were mounted to gauge attitudes and priorities in areas where ethics of science are at the centre of a widespread public debate. Rather than researchers seeking consumer input to research and development, public opinion was sought about appropriate constraints to research and development.

In contrast, individual consumers were assiduously recruited and supported by commercial interests in order to identify and prioritise topics for research and development in assistive technology.[63,75–79] Here considerable effort was invested in developing collaborative relationships with consumers who were seen as the end-product experts. This learning was not transferred to the NHS R&D programme for physical and complex disabilities. Here consumer involvement was far less developed and the research programme report concluded that a more balanced involvement of participants, including consumers, was needed in future.[55]

A third area notable not only for the number of examples we found, but also the degree of consumer involvement, was breast cancer. Breast cancer organisations have been exceptional in influencing the structures for managing research programmes in the USA,[83–86] Canada[82] and Australia.[58] It is probably relevant that breast cancer has a long history of advocacy and that, demographically, it affects a well educated group who would find engaging with the conceptual and organisational aspects of research agenda setting less challenging than many other groups.

Some types of interaction seemed to be associated with particular research foci. For instance, collaborations which evolved from consumer initiatives (Type E) were focused on condition specific issues such as HIV/AIDS,[89,90] breast cancer,[58,82–85,87] radiotherapy injury,[93] breastfeeding,[92] poor housing[88] and homelessness.[81] These conditions provided a focus for collective social action on a national, regional or local scale.

The stories of these interactions have been told both by consumers[83–85,87,90] and by researchers or research managers[63,82,92] directly involved, sometimes working together,[92] and by independent researchers[10,89,93] or independent committees.[67]

From these reports, we have gathered a variety of methods for consumer lobbying led by national consumer groups, advocacy groups and coalitions of consumers calling for research and research funding for their particular interests. They engaged with governmental bodies,[10,86] national[67] and regional research programmes[83,87] and teams of doctors and researchers.[81,88–90,92] They achieved community based research[88–90,92,93] and influential committee membership,[10,58,84–86] and multilevel participation[67,82,83,87,92] in national and regional programmes. The resulting output was an impressive list of changes in working methods and research priorities. Consolidated consumer action has also directly led to broad consultations (Type F).[10,95] As consumer involvement became more widely acceptable, research programmes took the initiative in contacting consumers. Consumer groups were invited to collaborate (Type A) with condition-specific research programmes about homelessness,[24] musculoskeletal problems,[29] breast cancer and HIV/AIDS.[28] Similar invitations have been limited to involvement through consultations (Type B), for instance about cancer,[47] asthma[60] and physical and complex disabilities.[135]

In summary, specific conditions have provided important foci for collective consumer action and, subsequently, considerable influence of public health sector research management structures. The commercial sector has also invested in consumers to direct research and development. This learning has not necessarily been transferred to research programmes not directly targeted by consumer campaigns or motivated by commercial interest. Opportunities remain for research programmes to invite very modest involvement from organised consumer groups for relatively little benefit or cost.

Broader research topics

Since the advent of consumer lobbying for condition-specific research, research programmes have sought to broaden the impact of consumer involvement either by inviting consumer groups to collaborate in research programmes with a broader focus (Type A), by conducting broader consultations (Types B and D) or by empowering traditionally marginalised individual consumers in collaborative relationships (Type C).

Consumer groups have been invited to collaborate in research programmes (Type A) characterised not by the health topic of the research, but by the type of research undertaken: health technology assessment[25,32] and systematic reviews of effectiveness.[28–31] The examples we found were national UK programmes[24,25,32,33,37] and Cochrane Collaboration review groups.[28–31] Collaboration initiated by research programmes was often conducted within a framework of organisational change, where the remit of work often included formal reflection on the processes employed to set the research agenda[25,32,33,37] Such programmes engaged national consumer groups, largely through committee membership. Where reflection focused on consumer involvement, it is clear these interactions led both to topics identified for research and recommendations for the process of consumer involvement. However, very little light is shed on the process of consumer involvement in priority setting across a broad range of health topics.

Broad consultations have also drawn on experienced consumer groups (Type B) to set the agenda for specific services (physiotherapy,[49] midwifery,[48] nursing[51]), for specific settings (occupational health and safety[54]), assessing health technologies,[32] organising services[33,74] and the issue of getting research findings into practice.[33,37]

Research that is broader than specific conditions has not generally been the prime interest of consumer groups as they are commonly organised around specific conditions. Methods for involving consumers in agenda setting across broad areas of research have been less influenced by consumers, and modelled more closely on the usual working practices of the research community: committee meetings, surveys or participative research.

Organisational setting for research
Geographical scope
National programmes in the UK have successfully engaged with national consumer groups and others within a framework of organisational change to set research agendas (Type A[24,25,32,33,37]). National consumer groups often had national networks informing them of their consumers' views and concerns, and they had the organisational structure and experience to engage with research programmes that make few concessions to newcomers. Consultations by national programmes of consumer groups (Type B) have been less successful[46,47,51] unless they have been led[37,42] or hosted[32] by consumers or had an independent facilitator.[58]

These national UK programmes had very different histories from national programmes that we found in **other countries**. Rather than adopting a framework of organisational change to set agendas and invite consumer group involvement in established programmes (Type A engagements), national programmes in Canada and the USA involved consumers in developing the structures and working practices in order to set research agendas (Type E engagements). There were very few Type E engagements in the UK. The only example was a policy change (and consequent new emphasis in research agenda) and a 5-year programme in response to lobbying by maternity service users.[10] This was a small achievement for consumers' interests in research agendas compared with the changes in breast cancer and HIV research in North America.[83–87,89]

We found two very different methods for engaging consumers on an **international** scale. Either effort was directed at consulting a representative population sample (Type D) to gauge general attitudes about the value of research,[68,69] or effort was made to develop working relationships with a small number of consumers across national boundaries, many of whom were active members of organised consumer groups (Type A). Once working relationships were established, this method led to prioritising topics in condition-specific areas,[28] identifying patient-defined outcomes[31] and developing collaborative working

practices[29] for systematically reviewing literature about effects of healthcare.

Two **regional** NHS programmes had broad health topics: inner city health and the health of older people. Both involved established community groups (with no special interest in health) in face-to-face encounters within the relevant geographical boundaries. The report of priority setting for inner city health (Type B) recorded consumers' criteria for setting priorities across health topics.[52,53] Broad priorities were also set for researching the health of older people after a collaborative exercise with associations for older people (Type A). Another regional programme in Nebraska engaged stakeholders in setting the agenda for school health services.[70] All these examples required considerable investment in the process, using facilitators with prior experience of consumer involvement in research[52,53] or carefully structured face-to-face encounters in addition to written communication over several months.[70]

Some UK national programmes have used regional structures to host workshops.[38,39,135] This allowed access to individual consumers, raised awareness of the programme and consumer involvement more widely and developed working relationships for the future.

Engagement on a **local** scale tended to invoke theories of empowerment to establish teamworking. Examples focused on evaluating services or voluntary sector groups (Type A[26]) or empowering Californian young people (Type C[61]) or Israeli elders (Type C[62]) to undertake their own research. Engagement on a local scale was found in developing countries where the predominant method for involving consumers was participatory research, and this was applied to environmental research for farming[66] and conservation.[71]

Comparing the examples above, the geographical scope seems to have had little influence on the choice of methods for involving consumers. Very different approaches (consumer initiated and research programme initiated) have been adopted on a national scale in different countries, and on an international scale (opinion polls and team work) for different purposes.

Institutional setting

Within the **UK NHS R&D programme**, the Type A collaborations and Type B consultations were the predominant approaches set within structures engaging with organisational change. Specific contributions from consumers were rarely recorded and only when organisational change specifically reflected on consumer involvement were any lessons learnt about the process.

The **professional bodies** that we found engaging consumers in agenda setting did so with simple consultation exercises, either a written consultation[49] or a single face-to-face event.[51]

University research teams also engaged in relatively small events, but several of these embraced the principle of empowerment through teamworking and participatory research (Types A, C and E[26,61,62,66,81]). Academics responded to consumer action with collaborative research[81,88,92] and independent research.[96,102]

It was **commercial organisations** who invested most in involving consumers in directing the research agenda. They followed a principle of partnership and engaged individual users with a variety of focus group consultations and priority-setting exercises[63,75–79]

The three national **charities** that we investigated in depth conducted their own consultative and collaborative exercises[42,64,129] amongst their own members. They influenced the research agenda by conducting their own research in collaboration with their own members,[129] by involving their members in prioritising research[64] or by feeding the results of their priority setting into national research programmes.[42]

Institutions have employed those consumer involvement methods most similar to their usual working practices: the NHS convened committees and conducted consultations; academics conducted research and engaged with consumers within an educational framework; commercial organisations worked with their customers; and charities worked with their members. Although this may mean that organisations have played to their strengths, their choice of methods have been conventional, and they may have much to learn from each other.

Which methods have contributed most knowledge?

Despite the weaknesses in the evidence and the potential confounding factors, we identified themes relating to success associated with each type of engagement. Some success was seen with most types of engagement, but only in certain circumstances. We considered knowledge of

		Consumers' degree of engagement			
		Consumer control	Collaboration	Consultation	Minimal
Researchers' degree of engagement	Inviting consumer groups		Type A: networked consumers, informed about task, taking a lead in consulting their peers, participating in facilititated discussion and reflections on the process → a record of consumer priorities and lessons about the methods for identifying them	Type B: direct and repeated involvement in debate, facilitated discussion with consumers with specific health interests → research topics identified and prioritised. Considerable time/resources working with general community groups → research topics identified/prioritised by broader community/marginalised groups	
	Inviting individual consumers		Type C: participative learning → few topics but highly relevant and directly leading to research	Type D: commercial investment in consultation → consumers' ideas and priorities informed development of technologies. Social research with patients in clinical setting → interventions and outcomes for evaluation agenda. Opinion surveys → public attitudes towards research	
	Responding to consumer action		Type E: consumer activism → new research agendas and consumer involvement in development of methods of involvement	Type F: well-established, politically aware groups sustained public debate → influence research agenda	Type G: consumers' persuasive language; or consumer authors in research media → new research priorities. Conflicts attract bad publicity
	Minor partner or absent	Type H: rich, poorly tapped pool of consumers' research ideas.			

FIGURE 11 *Characteristics of initiatives perceived as successful (causal relationships inferred)*

methods to be most advanced when we found both a record of consumers influencing research agendas and a reflection on the methods of involvement. The characteristics of methods perceived to be successful, and the terms in which this success was apparent, are presented in *Figure 11*.

For instance, there was reflection on methods and consumer influence when research programmes invited consumers to collaborate (Type A interactions), but only where the collaborating consumers were also conducting their own consultation of their peers[29,33,37] or where the research programme manager had considerable experience of working with consumer groups. Typically, under these circumstances, involving networked consumers who were informed about the task, took a lead in consulting their peers and participated in facilitated discussion and reflections on the process, led to a record of consumer priorities and lessons about the methods for identifying them. Between them, these specific episodes were set in international, national and regional programmes and they addressed condition-specific, population-specific and broader health research agendas.

Consulting consumer groups (Type B interactions) also enabled consumers to influence research agendas, but only when staff had considerable experience of consumer groups[52,53] or where the consumer groups had considerable experience of research.[51] Direct and repeated involvement in debate facilitated discussion with consumers with specific health interests and led to research topics being identified and prioritised. Greater effort in terms of time and resources was needed when working with general community groups, although here too the broader community, including marginalised groups, could identify and prioritise research.

Empowering individual consumers to collaborate (Type C interactions) also showed some successes, whether the underlying philosophy was participative research in an academic setting[61,62,66] or consumerism and commercial interest.[75] Participative learning led to few topics, although these appeared highly relevant to consumers and led directly to research.

Similar outputs in terms of the research agenda and reflections on the process were achieved with consultations of consumer groups (Type D interactions) where the driving principle was participative research[71] or commercial success.[75–78] Conventional social research methods were easily applicable to patients in clinical settings for identifying interventions and outcomes for an evaluation agenda.[73,73]

Where research programmes have responded to consumer action with collaboration (Type E) we saw that consumers appeared to have influenced the research agenda and the processes of involvement.[10,81,84–86] Consultations in such circumstances (Type F) appeared less successful in these terms, although well established, politically aware groups that managed to sustain public debate did influence research agendas.[10,50,95]

We found isolated examples of consumers influencing research agendas through their use of emotive language addressed to researchers or publishing in the research media.[96] However, independent consumer action more often attracted criticism and bad publicity for services or research.[97,107]

Independent consumer action (Type H), whether in conducting research[129] or setting research priorities,[42] was successful in identifying consumer priorities although in these circumstances consumer groups also needed to influence a programme of research. In these instances they either conducted their own programme of research[129] or they were able to offer suggestions to other programmes.[42,49,59] However, this remains a rich but poorly tapped pool of consumers' ideas for research.

Many successful examples of consumer involvement that either contributed to our knowledge about consumer priorities or methods for involving them in setting research agendas shared a common theme of investment in, and experience of, working relationships. This investment and experience was evident in various forms, where:

- Engagement was collaborative and consumers were empowered to play leading roles or researchers drew on extensive experience of working with consumers.
- Consultations were led by researchers with extensive experience of working with consumers, or consumers drew on extensive experience of campaigning and/or research.
- Time and effort was invested in facilitating extended debate.

Chapter 7
Discussion

The current study has identified reports of consumers contributing to R&D agenda setting, some of which have documented consumers' ideas and priorities, and some of which provided lessons for developing methods of involvement. This evidence depends largely on the reports of people directly involved in agenda setting, either researchers, research managers or consumers. Circumstances and methods appeared to present a range of advantages and disadvantages. Much more rarely we found independent reports that also documented advantages and disadvantages.

Success in terms of consumers actually identifying and prioritising research topics, rather than merely being present (in person or through correspondence) during the process, appears to have been related to the degree of consumer participation and control. Topics and priorities were more often documented following collaborations rather than consultations, particularly where communication between consumers and research programmes, or amongst consumers themselves, was supported by investment in time, training, consumer networks and iterative discussion.

The strengths of the current study include the systematic and exhaustive search of electronic bibliographic databases, extensive networking within the UK and the systematic approach to describing and analysing the reports found. It also rests on having contacted 250 consumers and researchers who were important for providing up-to-date information in a rapidly developing field. The majority of the reports that were sufficiently detailed to include in the review were found through consumer or researcher networks. Those reports that were identified only through electronic searches of bibliographic databases were more often not set within a narrow definition of health services. It was by electronic searching that we identified examples of consumer involvement in research agenda setting for occupational safety,[54] biotechnology,[68,69,95] indoor and outdoor[61,107] environmental health, school health,[70] conservation,[71] science[80] and engineering,[76,79], homelessness[81] and social research.[62] Few of these used the combination of

committee membership and written consultation so commonly chosen by Advisory Groups convened specifically to set the initial NHS R&D agenda. Rather, they provided descriptions of alternatives such as town meetings;[54] training and support for conducting research[26,62] and a survey of priorities;[81] representative opinion polls;[68,69,95] questionnaire and workshop;[70] interviews, focus groups and workshops;[50,71] participatory research;[61] consensus development methods;[75,76,78] and toll-free telephone lines.[95]

Searching electronically beyond narrow definitions of health also highlighted how relatively few examples of health research agenda setting have been formally reported in peer-reviewed journals. This may reflect the lack of importance attached to this aspect of agenda setting hitherto.

We sought purposeful and opportunistic examples of consumer involvement in setting research agendas. This approach had an inherent bias towards successful interactions. Opportunistic interactions were by definition successful, and purposeful ventures that were unsuccessful were less likely to be reported. Our search was directed towards interactions of consumers and the research agenda, and we reviewed the methods reported. This approach highlights those methods that have been (usually more or less successfully) applied to involving consumers in setting the research agenda. It obviously does not highlight those methods that have not been reported, whether this was because they have not been attempted or because they have not been successful. Nor has it captured the numerous opportunistic episodes where consumers influenced the research agenda although it was not reported in these terms: excluded was a rich literature of consumers actively participating in research.

Related literature

These findings have been complemented by other reviews of published and unpublished literature. Although we have not been able to find any previous systematic attempt to review methods for involving consumers in setting research agendas, a

survey of UK research programmes has identified both matches and mismatches in consumer priorities for research.[35] This review defined mismatches as differences or disagreements in perception, opinion, view or practical decision concerning the problems or needs to be addressed by research. The authors concluded that such mismatches and the implications that flow from them have been under-recorded. Very few of the studies they found allowed for direct comparisons to be drawn between the priorities of professionals and consumer groups. As with the current study, the evidence collated was weak but indicative. Consumers would seem to support research on broader social and environmental influences, on alternative treatments and on long-term health problems. Mismatches may be more prevalent in respect of social and organisational aspects of healthcare than in the more basic biosciences.

Another report particularly pertinent to consumer involvement in health research agenda setting in the UK is the guidelines for researchers published by Consumers in NHS Research. This differs from the current work in being based not on a review of international literature but on the pooled experience of consumers, academics and NHS staff. Their experience included direct involvement in citizens' juries, community development and its evaluation, action research and consumer involvement in systematic reviewing, research management and guideline development; across social work, education, genetics, maternity and disability. This experience provided a route for purposively sampling successful examples of consumer involvement to illustrate the guidelines.

The current review adds to that document by providing evidence in terms of outputs from more and less successful examples of consumer involvement in agenda setting exercises. It supports their assertion that "the task of identifying a research topic should be a dialogue … the best way to involve consumers is face-to-face".[4] The current review provides a broader range of examples of consumer involvement in agenda setting leading to research projects, and several examples where a broad range of consumers were involved in agenda setting. The current review supports Consumers in NHS Research's assertion that the choice of consultation, collaboration or consumer control as an approach depends on the researchers, the consumers, the research method and the funding body. It also supports their recommendation that each exercise of consumer involvement should be

evaluated. However, the current review shows that, so far, despite extensive experience of consultation exercises particularly in the NHS, least has been learnt from these simpler methods of involvement in research agenda setting, compared with experience of collaboration or consumer control. This may have disheartening consequences, particularly as least is learnt about how to involve consumers simply but well, and most is learnt about those methods that require greatest investment. Most reports of consumer involvement in research agenda setting are not sufficiently detailed to judge the extent to which they met the guidelines prepared by Consumers in NHS Research. This lack of detailed reporting of both the methods and the outputs suggests an additional principle of reflecting on experience in order to learn, share the lessons and build a rigorous and publicly accessible knowledge base about consumer involvement in research agenda setting.

By comparing what we found with Mullen's distinction between methods for engagement and methods for eliciting and aggregating findings,[9] we see that reports of consensus development are notable for their absence. Searching for reports of consensus development and reviewing them for their applicability to consumer involvement in research agenda setting could fill this gap, or direct research to fill it. When this approach was taken to study consensus development for clinical guidelines, Murphy and colleagues drew a number of conclusions which might be applicable to research agenda setting.[8] These conclusions related to selecting the participants, choosing and preparing background information, structuring the interaction and synthesising individual judgements. However, Murphy and colleagues found few studies that specifically related to consumers. Where literature addressing public preferences has been reviewed, it was restricted to eliciting these preferences and did not address the challenge of integrating public preferences into decision-making.[7] There is a need for more detailed study of consumer involvement in consensus development.

In terms of implementation, our review concurred with the findings of a survey of health bureaucracy consultations.[8,136] The key conditions that the survey highlighted as enabling an organisation to consult effectively were similar to those in involving consumers in research agenda setting: official endorsement of consultation at senior levels; staff with expertise, experience and skills in consultative practices; constructive and on-going

relationships with communities; valuing the knowledge and experience of community members; and representative mechanisms which recognise and respect difference. Other conditions that may also be transferable to consumer involvement in research agenda setting were decentralised and devolved decision-making for greater accessibility, responsiveness and flexibility; simple, clear and consistent structures and procedures; stability in functional responsibilities and continuity of staff; and balanced requirements for economic efficiency and social justice.

There is little direct link between many of the reports included in this review and the broader relevant theoretical or empirical literature. The exception is the link with Arnstein's work, which has penetrated policy discourse about consultation, collaboration and consumer control.[18] Other than this, consumer involvement initiatives in research agenda setting appear to be developing largely in isolation, with little direct experience or guidance to build on. This is reminiscent of earlier literature about self-help groups where "the bulk of the literature consists of simple, descriptive case studies, with little or no attempt at quantification and still less attempt to test hypotheses about relationships using quantitative data. There is a dearth of comparative studies as well … [and] it is fair to say that most of the researchers in the field of self-help group study seem essentially oblivious of the large extant literatures on social movements and voluntary action more broadly".[3] This lack of grounding in prior research is unsurprising, since advances in this field currently rely largely on enthusiasts amongst consumers and managers of research. Indeed, the main weakness of our findings stems from the dearth of formal studies by non-participants. Most reports were prepared by participant researchers or managers and a few by participant consumers. This balance of participant authors is likely to have biased reporting in favour of successful ventures, perhaps glossing over more difficult experiences. In some instances, reports or interviews offered both perspectives on the same events. While there was corroboration, there was also some disagreement.

Potential impact of consumer involvement

We have tried to evaluate consumer involvement by addressing its impact. We were disappointed to find how rarely records had been kept of consumers' ideas and priorities: far more often kept by consumers than by researchers. Where records had been kept, even when they matched the subsequent research agenda, it was not possible to determine the extent to which consumers had influenced the agenda, if at all. Even more difficult was determining whether the research agenda led to research which matched consumers' priorities. This was because such information was not recorded in the same documents. Scanning NHS R&D websites identified some research that appeared to match a few consumer priorities, but whether consumers had been influential was impossible to tell.

Another potential impact of consumer involvement was changes in structures and processes for setting agendas. Most radical were examples in North America, where new research programmes were designed in partnership with consumers. A little more common was consumer involvement in designing procedures for consumer involvement: this occurred in some Cochrane Review Groups. Typically within the NHS R&D programme, consumer involvement was not even reported in the reflections of the advisory panels.

The most far-reaching potential impact could be on the management, conduct and findings of the funded research and subsequent changes in practice and health outcomes. A tenuous link can be traced from consumer concerns about perineal care during childbirth. These were raised by the NCT in a 1981 survey of members' experiences of episiotomy, and again in 1993 with a survey of women's experiences and midwives' practices for perineal care. The initial survey prompted a trial of episiotomy that was reported in 1984.[137,138] Episiotomy rates fell.[125] Research about perineal repair was summarised in two Cochrane systematic reviews.[139,140] For these reviews, consumer views regarding what outcomes they would expect were sought from local focus groups, members of the NCT and other postnatal support groups. The main outcomes of interest from consumers' point of view were the extent of short- and long-term pain, the removal of suture material and the resumption of pain-free intercourse. The evidence from one of these reviews[140] was used by a midwife to change the stitching practice in her hospital and her description of this work won her the Cochrane Library prize in 1998. This story spread over 4 years from expressed concern about episiotomy rates to trial findings in the first instance, and over 5 years from expressed concern about perineal repair to changed practice in the second.

Far more immediate impact has been seen in examples of participative research where consumers identified the questions and worked with researchers to find the answers. Farmer participatory schools in developing countries could identify problems, compare methods and have the answers in a single season. Similarly, Californian young people addressed their chosen topics within a summer break from school.

In summary, what we know about the advantages and disadvantages of methods for involving consumers in agenda setting rests on weak short-term evidence and almost entirely speculative long-term evidence.

Chapter 8
Conclusions and recommendations

The conclusions and recommendations are drawn from the findings of the literature synthesis and the analysis of the UK cases. They rest on evidence that is weakened by the difficulty of accessing literature on consumer involvement, the patchy nature of the research and the lack of independent reports or rigorous studies.

Nevertheless, it is clear that consumers can identify and prioritise research topics, despite the technical nature of research and the added complexity of debating the relative importance of gaps in research evidence. However, attempts to involve consumers were not always successful, either in gathering consumers' ideas or in using consumers' ideas to influence research agendas, so we have tried to identify common difficulties and possible solutions.

In the absence of comparative studies, we cannot conclude that any methods are more or less advantageous than others. The choice of approach to engagement and methods of interaction will depend on the researchers, the consumers, the research task, the funding body and the social context and values informing the research process. However, there is some indication that different methods may be associated with specific advantages and disadvantages. We can also draw conclusions about how methods have been implemented in advantageous or disadvantageous ways. Most of our conclusions relate to the uncertainties of knowledge in this area and inform our recommendations for research.

Implications for research programmes

Conclusions about consumer involvement in research agenda setting are not fundamentally different from conclusions about consumer involvement in research or service planning more widely, despite the added complexity of prioritising gaps in evidence. Research programmes have sufficient collective experience of involving consumers to plan their agendas, working directly or indirectly with consumers. Appropriate methods depend upon the tasks to be undertaken, the consumers to be involved and the support required.

Productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices. Support and training may be adapted from programmes developed to enable multidisciplinary groups to discuss evidence for service planning or for consumers to develop skills and confidence to influence healthcare decisions.

The more that consumers are involved in determining how this is to be done, the more research programmes will learn from consumers and about how to work with them. Unless consumer involvement is to be a late addition to a programme (apparently one of the least effective approaches), planning for consumer involvement and securing the necessary investment need to start at the same time as planning for the programme as a whole. Where programmes are already established and consumer involvement is necessarily a late addition, the programme may face considerable challenges.

Although the choice of methods for involving consumers should be made in discussion with consumers themselves, this discussion can be informed by the experiences collated in this review. More success might be expected if research programmes embarking on collaborations approach well-networked consumers and provide them with information, resources and support to empower them in key roles for consulting their peers and prioritising topics. To be worthwhile, consultations should engage consumer groups directly and repeatedly in facilitated debate; more resources and time are required if consumers are drawn from groups whose main focus of interest is not health. Participative research methods can either lead to a small number of completed research projects or can be applied to designing and implementing novel research management structures for agenda setting. Well-developed commercial consultation or social research methods can engage individual consumers; opinion surveys tend to be less informative in setting research agendas.

There are barriers to be overcome whatever the method for engagement or forum for exchange of ideas: poor representation of consumers;

consumers' unfamiliarity with research and research programmes' unfamiliarity with consumers; negative attitudes and poor working relationships; difficulties in communication and time constraints. These barriers can largely be overcome with good leadership, purposeful outreach to consumers, investing time and effort in good communication, training and support, thereby building good working relationships and building on experience.

Some methods, such as occasional consultations, do not lend themselves to long-term investment, and these approaches have more often failed to show the advantages of enthusiasm for involvement, or increased knowledge about consumers' priorities or constructive ways of working with them. Occasional consultations, conducted without input from consumers themselves, risk disappointing outcomes and cynicism.

There is an urgent need for research programmes to improve their record on reflection and documentation of consumer involvement if they are to learn from their experience anything about consumers' priorities and appropriate methods for involving them. Past experience shows that more has been gained from reflection and documentation when consumers have played a part in this too. Reports should include details of the participants, approaches to engagement, forums for discussion, methods for decision-making and the context of the work.

Implications for consumers

Organised consumer groups capable of identifying research priorities need to find ways of introducing their ideas into research programmes. Consumers may be disheartened by their apparent lack of influence on UK research programmes. They should be aware that responding to written consultations may not be a good use of their time. If they wish to be involved in setting research agendas they may prefer to offer more time in order to collaborate. As collaborators they could seek funding to conduct consultations of a broader range of consumers in order to record consumers' views and better inform the research programmes. They should be aware that consumers making efforts to (re)design structures and procedures has led to greater influence over research agendas. Consumers are particularly well placed to reflect on their experience of research agenda setting in order to build the evidence about consumers' priorities and methods for involving them.

Recommendations for research

This review has provided vivid descriptions of poor consumer representation, poor communication, tenuous working relationships, attitudes not wholly welcoming or supportive of consumers and serious time constraints for involving consumers. Commitment from senior staff, broad consumer involvement, investing time and resources in meetings to develop working relationships, communication, training and support and building on experience were all seen as valuable. **We recommend** research to develop and evaluate different training methods, information and education and other support for consumers and those wishing to involve them.

Where consumers are capable of identifying and prioritising research topics, they have had relatively little impact on research agendas. **We recommend** research addressing the barriers to consumers' ideas influencing research agendas.

Given that the evidence about consumer involvement in research agenda setting rests largely on reflective reports by participants, **we recommend** that research programmes embarking on working with consumers do so within an ethos of reflexive research. At a minimum they should involve consumers in reflecting on and reporting the process and outcome. Whenever possible they should involve consumers in considering the methods and implications of working together both in advance and with hindsight. There is also a place for independent researchers to work with research programmes and consumers to investigate and record working practices, and to attempt to assess the impact (and costs) of such involvement. Consumers should be involved in conducting and reporting this work.

This review found very few formal evaluations of consumer involvement in research agenda setting. These employed retrospective analysis or action research. Therefore, **we recommend** prospective comparative studies of different methods for involving consumers.

We found very few reports detailing how decisions were made. Exceptions included Delphi studies in face-to-face or written consultations. **We recommend** that research about collective decision-making be further advanced by addressing the processes and outcomes of consensus development that involve consumers.

Acknowledgements

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Appendix I

Search strategy for agenda setting report

Commercial and specialist database searches

Medline (UnixSPIRS): 1989 – August 1999

No.	Search
#1:	RESEARCH / all subheadings
#2:	explode RESEARCH-DESIGN / all subheadings
#3:	explode HEALTH-SURVEYS / all subheadings
#4:	TECHNOLOGY-ASSESSMENT-BIOMEDICAL / all subheadings
#5:	DELPHI-TECHNIQUE / all subheadings
#6:	explode CONSENSUS-DEVELOPMENT-CONFERENCES / all subheadings
#7:	FOCUS-GROUPS / all subheadings
#8:	DELPHI
#9:	TECHNIQUE*
#10:	DELPHI TECHNIQUE*
#11:	DELPHI
#12:	STUD*
#13:	DELPHI STUD*
#14:	WORKSHOP*
#15:	NOMINAL
#16:	GROUP*
#17:	NOMINAL GROUP*
#18:	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #10 or #13 or #14 or #17
#19:	STAKEHOLDER*
#20:	CONSUMER
#21:	PARTICIPATION
#22:	CONSUMER PARTICIPATION
#23:	USER
#24:	GROUP*
#25:	USER GROUP*
#26:	CONSUMER
#27:	INVOLVEMENT
#28:	CONSUMER INVOLVEMENT
#29:	PATIENT
#30:	PARTICIPATION
#31:	PATIENT PARTICIPATION
#32:	CONSUMER-PARTICIPATION / all subheadings
#33:	CONSUMER-ADVOCACY / all subheadings
#34:	CONSUMER-ORGANIZATIONS / all subheadings
#35:	#19 or #22 or #25 or #28 or #31 or #32 or #33 or #34
#36:	#35 and #18

Key: *, truncation.

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EMBASE (OVID): 1988 – August 1999

Set	Search
1	consumer.sh.
2	exp consumer/
3	exp research/
4	exp health care organization/
5	health care organization.sh.
6	health services research.sh.
7	health care policy.sh.
8	health care planning.sh.
9	consumer$.tw.
10	research.tw.
11	delphi technique$.tw.
12	consensus.sh.
13	public opinion.sh.
14	public participation.sh.
15	(research adj5 priority).tw.
16	(research adj5 priorities).tw.
17	(research adj5 agenda).tw.
18	(research adj5 agendas).tw.
19	patient participation.tw.
20	consumer participation.tw.
21	user group$.tw.
22	(consumer adj5 advoca$).tw.
23	consultation exercise.tw.
24	consumer organisation$.tw.
25	consumer organization$.tw.
26	consumer group$.tw.
27	self-help group$.tw.
28	consumer involvement.tw.
29	stakeholder$.tw.
30	lay.tw.
31	(lay adj5 participa$).tw.
32	(lay adj5 participat$).tw.
33	(lay adj5 involv$).tw.
34	delphi stud$.tw.
35	consensus development.tw.
36	consensus conference.tw.
37	staticised group$.tw.
38	statisticed group$.tw.
39	(citizen$ adj jur$).tw.
40	consultation round$.tw.
41	postal consultation$.tw.
42	workshop$.tw.
43	(workshop$ adj10 research).tw.
44	focus group$.tw.
45	consensus method$.tw.
46	1 or 9 or 13 or 14 or 19 or 20 or 21 or 22 or 24 or 25 or 26 or 27 or 28 or 29 or 32 or 33
47	3 or 5 or 6 or 7 or 8 or 11 or 12 or 15 or 16 or 17 or 18 or 23 or 34 or 35 or 36 or 40 or 43 or 44 or 45
48	research topic$.tw.
49	47 or 48
50	49 and 46

Key: sh, controlled terms; tw, search in title, abstract and controlled terms; $, truncation.

CINAHL: 1982 – June 1999

Set	Search
1	"Consumer-Advocacy"/all subheadings
2	"Consumer-Attitudes"/all subheadings
3	"Consumer-Organizations"/all subheadings
4	"Consumer-Participation"/all subheadings
5	"Consumers"/all subheadings
6	"Public-Opinion"/all subheadings
9	consumer involvement in ab, ti
12	consumer participation in ab, ti
15	patient participation in ab, ti
18	patient involvement in ab, ti
21	user group* in ab, ti
23	stakeholder* in ab, ti
26	lay involvement in ab, ti
29	lay participation in ab, ti
30	"Research"/all subheadings
31	"Human-Genome-Project"/all subheadings
32	explode"Research-Disciplines"/all subheadings
33	explode"Research-By-Type-and-Subject"/all subheadings
34	"Research-Ethics"/all subheadings
35	"Research-Measurement"/all subheadings
36	"Research-Measurement"/all subheadings
37	"Research-Methodology"/all subheadings
38	"Study-Design"/all subheadings
39	"Research-Personnel"/all subheadings
40	"Research-Priorities"/all subheadings
41	#30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40
42	#1 or #2 or #3 or #4 or #5 or #6
43	#9 or #12 or #15 or #18 or #21 or #23 or #26 or #29
44	#42 or #43 [ALL CONSUMER TERMS]
45	"Seminars-and-Workshops"/all subheadings
46	"Focus-Groups"/all subheadings
47	"Delphi-Technique"/all subheadings
48	#45 or #46 or #47
51	consensus method* in ab, ti
54	consensus conference* in ab, ti
57	committee membership in ab, ti
60	working group* in ab, ti
63	advisory group* in ab, ti
66	consultation exercise* in ab, ti
68	#51 or # 54 or #57 or #60 or #63 or #66
69	#41 or #48 or #68 [ALL RESEARCH TERMS]
70	#44 and #69 [BASIC SEARCH]

Key: ab, abstract; ti, title; *, truncation.

SSCI (BIDS ISI): 1989 – November 1999

All searches free text (searches look for search string in keyword, title and abstract fields). A facility for searching for keywords only was not available through the BIDS ISI platform. Search strings were also restricted in length.

Set	Search
1	consumer participation
2	lay participation
3	consumer involvement
4	consumer*
5	consumer advocacy
6	consumer group*
7	consumer organization*
8	consumer organisation*
9	self help group*
10	public opinion
11	public debate*
12	stakeholder*
13	lay involvement
14	patient group*
15	research charit*
16	user group*
17	patient organization*
18	patient organisation*
19	patient bod*
20	research
21	research agenda*
22	research priorit*
23	agenda setting
24	priority setting
25	research program*
26	delphi method*
27	delphi technique*
28	consensus method*
29	consensus conference*
30	consensus development conference*
31	working group*
32	advisory group*
33	workshop*
34	committee membership
35	consultation round*
36	consultation exercise*
38	postal consultation*
39	focus group*
40	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
41	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
43	21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
44	31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39
45	43 or 44 [ALL SPECIFIC RESEARCH TERMS (excluding 'research')]
46	40 and 45 [1st SET CONSUMER TERMS COMBINED WITH RESEARCH TERMS]
47	41 and 45 [2nd set CONSUMER TERMS COMBINED WITH RESEARCH TERMS]

Key: *, truncation.

ASSIA (Bowker Saur A & I): 1986 – August 1999
Consumer terms combined with research terms

Set	Search
1	ft = self help group*
2	ft = public opinion
3	ft = public debate*
4	ft = stakeholder*
5	ft = patient group*
6	su = consumer*
7	su = consumer satisfaction
8	su = consumer products
9	su = consumer protection
10	cs = 7 or cs = 8 or cs = 9
11	cs = 6 not cs = 10
12	ft = user group*
13	ft = service user*
14	ft = consumer*
15	su = research*
16	su = medical research
17	ft = research priorit*
18	ft = research agenda*
19	ft = agenda setting
20	ft = priority setting
21	ft = delphi*
22	ft = consensus conference*
23	ft = research
26	cs = 15 or cs = 16 or cs = 17 or cs = 18 or cs = 19
27	cs = 20 or cs = 21 or cs = 22 or cs = 23 or cs = 26 [ALL CONSUMER TERMS]
28	cs = 1 or cs = 2 or cs = 3 or cs = 4 or cs = 5
29	cs = 11 or cs = 12 or cs = 13 or cs = 14 or cs = 28 [ALL RESEARCH TERMS]
30	cs = 29 and cs = 27

Key: ft, in title, abstract and controlled terms; su, controlled terms; cs, combine set; *, truncation.

Consumer terms not combined with research terms[a]

No.	Search string
1	ft=consultation exercise*
2	ft=consumer participation
3	ft=lay participation
4	ft=lay perspective*
7	ft=consumer involvement
11	ft=citizen* jur*
12	cs = 1 or cs = 2 or cs = 3 or cs = 4
13	cs = 7 or cs = 11 or cs = 12

[a] The Barker Saur database platform restricts the number of search strings for any one search, necessitating two separate searches.

Caredata: 1989 – June 1999

1	'user involvement' AND 'research' in keywords field
2	('research' AND 'report') in abstract field AND 'user involvement' in keywords field
3	('research' AND 'review') in abstract field AND 'user involvement' in keywords field
4	('Priority' OR 'agenda' OR 'priorities' OR 'agendas') in abstract field AND 'user involvement' in keywords
5	1 OR 2 OR 3 OR 4

ERA database (held by EPPI-Centre)
Search term: 'research priorities'.

Centre for Reviews and Dissemination Health Technology Assessment database (via International Network of Agencies of HTA)
Search terms 'consumer' OR 'consumers'.

Publications on the Internet (POINT) database published by the Department of Health
Search terms '(consumer AND research) OR (user AND research) OR participation OR involvement'.

Handsearching

All conducted November 1999.

1. Abstracts of the 3rd International Conference on the Scientific Basis of Health Services.
2. Abstracts of the VII Cochrane Colloquium Conference.
3. Conference reports since 1989 of the International Society for Technology Assessment in Health Care (via ISTAHC database, URL http://www.istahc.org/en/dataind.html, consumer in title or in abstract).
4. Oliver and Buchanan (1997, ADD full reference report to Standing Group Consumers in NHS Research).[56]
5. C Grant-Pearce *et al*., (1998, ADD full reference PREST report).[35]
6. Dixon, Peart and Carr-Hill (1999, ADD full reference York Database).
7. H Bastian, The power of sharing knowledge: consumer participation in the Cochrane Collaboration, December 1994, ADD full reference.

Appendix 2

Tabular synthesis of findings

Type A Inviting consumer group involvement through collaborations

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
A.1 Committee membership								
Power *et al.*, 1999[24] *Case investigated in more depth for UK episodes (see Chapter 5)*	*HEA*		*Condition specific: homelessness*	*UK, national*	*Government-funded body*			*Experience of collaboration led to research project*
NHS Management Executive, 2000[25]	New and Emerging Technologies		Health technologies	UK, national	NHS R&D			
A.2 Teamworking								
Lackey *et al.*, 1997[26]	Centre for Health Policy and Programme Evaluation, University of Wisconsin Medical School	Activists from grass roots organisations, service users, volunteers	Evaluation of empowerment	USA, local	Academia		Empowerment	Consumer and academic criteria for evaluating empowerment
A.3 International collaboration								
Kelson, 1999[31]	Cochrane Review Groups	Consumer groups	Condition specific	International	Academia		Partnership	Consumers identifying patient-defined outcomes for some groups
Kelly, 1998[29]	Cochrane Musculoskeletal Review Group	National consumer groups	Condition specific: musculoskeletal problems	International	Academia		Partnership	Consumer suggestions for research and ways of collaborating

| Author(s) | Participants | | Research focus | Organisational setting | | Consumer involvement | | |
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Ghersi et al., 1999[28]	Four Cochrane Review Groups	National review groups	Condition specific: musculoskeletal; breast cancer; HIV/AIDS; consumers and communication	International	Academia		Partnership	
Hirst, 1997[30] Case investigated in more depth for UK episodes (see Chapter 5)	Cochrane Diabetes Review Group	National review group: IDDT	Condition specific: diabetes	International	Academia		Partnership	
A.4 Combining collaboration and consultation								
Oliver, 1995;[32] NHS Management Executive, 1995[33]	NHS R&D implementation of research findings	Individual consumers, consumer representatives and community groups	Service development	UK, national	NHS R&D		Organisational change	Consumers identified: promising methods for involvement; topics for research; reflections on agenda-setting process
CRDC Advisory Group on Mother and Child Health, 1994;[38] Trent Regional Health Authority, 1994;[40] NHS R&D Directorate, 1994[39]	NHS R&D Mother and Child Health	Consumer groups and individual service users	Mother and child health	UK, national	NHS R&D	Area with history of consumer involvement	Organisational change	Research agenda published without detailing consumer contributions

continued

| Author(s) | Participants | | Research focus | Organisational setting | | Consumer involvement | | |
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Hills and Farrell, 2000[34]	Department of Health Health in Partnership	Patient and carer groups	Service development	UK, national	NHS R&D		Partnership	Research agenda focus on lay involvement in 3 areas: individual treatment and carers, service development, lay involvement in staff training
Oliver, 1998[32] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS HTA*	*National consumer groups; journalist*	*Health technologies*	*UK, national*	*NHS R&D*		*Organisational change; learning organisation*	*Three consumer topics identified; research priorities published without detailing consumer contributions*
Breckenridge, 1994[45] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D Primary Dental Care*	*Members of public, consumer groups*	*Dental care*	*UK, national*	*NHS R&D*		*Organisational change; learning organisation*	*Identified areas of concern to consumers*
Doble, 1999;[36] Northern and Yorkshire Regional Research and Development Programme, 1999[122–125] *Case investigated in more depth for UK episodes (see Chapter 5)*	*Northern and Yorkshire Older People*	*Older people's groups*	*Population specific*	*UK, regional*	*NHS R&D*	*Manager has personal experience of voluntary sector*		*Five topics prioritised, without specifying contributions of consumers. Grant applications asked for 'recognition of the user perspective'*

Type B Inviting consumer group involvement through consultation

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
B.1 Written consultations								
NHS Management Executive, 1994[47]	NHS R&D Cancer	16 patient interest groups	Condition specific: cancer	UK, national	NHS R&D		Organisational change	Research agenda published without detailing consumer contributions
Advisory Group on Setting Priorities in Cardiovascular Disease and Stroke R&D, undated[46]	NHS Cardiovascular Disease and Stroke	Wide range of consumer organisations	Condition specific: cardiovascular disease and stroke	UK, national	NHS R&D		Organisational change	Research agenda published without detailing consumer contributions
Chartered Society of Physiotherapy, 1998[49]	Chartered Society of Physiotherapy	Recorded on ASLIB	Service specific: physiotherapy	UK, national	Professional body without allocated research funding		Organisational change	Consumer-identified research topics (not unique to consumers)
Sleep and Clark, 1993;[48] Sleep et al., 1995[43]	NPEU: midwifery research	Maternity consumer groups		UK, national	Academia		Reflective professional practice	Research agenda published without detailing consumer contributions
B.2 Single face-to-face consultations								
Oliver, 1995[37] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D HTA*	*National consumer group*		*UK, national*	*NHS R&D*	*Manager had experience of consumer involvement*	*Organisational change*	*3 research topics from consumer group submitted to the programme – not prioritised*

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Poulton, 1994[51]	Royal College of Nursing	National consumer groups		UK, national	Professional body		Organisational change	Consumer-suggested research topics and views on methods of involvement
NHS Management Executive, 1995;[33] Oliver, 1995[37]	NHS R&D implementation of research findings	Individual consumers and representatives of consumer and community groups		UK, national	NHS R&D		Organisational change	Consumer-identified research topics, promising methods for consumer involvement
Jeste et al., 1999[57]	Geriatric mental health	Advocacy groups	Geriatric mental health	USA, national				Research agenda published without detailing consumer contributions
B.3 Multiple face-to-face consultations								
Rosenstock et al., 1998[54]	NIOSH	'Stakeholders', e.g. employees		USA, national	Professional body		Health promotion, community development	Research agenda published without detailing consumer contributions
NHS R&D, undated[55] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D Physical and Complex Disabilities*	*National consumer organisations and individual users and carers*		*UK, national*	*NHS R&D*		*Organisational change*	*Research agenda published without detailing consumer contributions. Lessons for consumer involvement*

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Wiles and Brownfoot, 1997;[52] NHS Executive North Thames, 1996[53]	North Thames Inner City Health	Established community groups and voluntary sector groups		UK, regional	NHS R&D			Consumers set criteria for prioritising; 3 broad priorities outlined and key messages for research
Schibeci et al., 1999[50]	Public Perceptions of Biotechnology, Perth, Australia	Consumer groups and voluntary organisations	Biotechnology	Australia, regional	University			Consumer concerns about broader contextual, social and ethical issues
B.4 Combining face-to-face and written consultations								
NHS Management Executive, 1994[59]	NHS R&D interface of primary and secondary care	National carers' group		UK, national	NHS R&D		Organisational change	Agenda item: "systematic evaluation of patients' and carers' needs and views of services"
Department of Health, 1995[60]	NHS R&D Asthma	Consumer groups for asthma		UK, national	NHS R&D		Organisational change	Research agenda published without detailing consumer contributions

Type C Inviting individual consumer involvement through collaboration

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
C.1 Teamworking								
Schwab, 1997[61]		Young people from low-income families	Teamworking – participatory action research	USA, local	Academia		Empowerment/ partnership/ power sharing	Young people selecting and framing issues for own research
Glanz and Neikrug, 1995[62]	Gerontological Research	Older people	Training programme	Israel, local	Academia		Empowerment	Older people doing own research; articles published in journals
Newroe and Oskarsdottir, 1997[63]	Consumer Assistive Technology Transfer Network	Disabled people	Committee membership	USA, national	Commercially and publicly funded research and development		Consumerism, partnership	Consumers defined problems and tested prototype solutions
Alzheimer's Society, undated;[64] Harvey, 2000[65]	Alzheimer's Society	Alzheimer's patients and carers	Network, Internet and training	UK, national	Charity			Consumer priorities posted on WWW to inform research grant applicants
Kimani et al., undated[66] *Case investigated in more depth for UK episodes (see Chapter 5)*	*CABI Bioscience – Integrative Pest Management*	*Farmers*	*Farmer participatory training and research*	*Developing countries, local*	*Academia*		*Empowerment, learning organisation*	*Farmer identified research topics. Farmers become 'active learners'*

Type D Inviting individual consumer involvement through consultation

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
D.1 Opinion polls								
European Commission, 1993[68]	European Biotechnology	Representative sample over age 15 years	Biotechnology	International, Europe			Ethics	Public's preferences for biotechnology identified
Macer, 1994[69]	Public attitudes towards IVF, genetic engineering, biotechnology	Representative sample	Biotechnology	Japan, national			Ethics	Public's preferences for biotechnology identified
D.2 Face-to-face encounters on a small scale								
Cramer and Iverson, 1999[70]	Nebraska School Health	'Stakeholders' including student, parent	Setting specific: schools	Canada, regional	School Health Authority		Health promotion/ community development; public accountability	Research agenda published without detailing consumer contributions
Hannah et al., 1998[71]	Conservation in Madagascar	Farmers, ecotourism operators, forest gatherers	Environmental conservation	Developing country, local	Academia		Participatory research	Identified research needs without detailing consumer contributions
Wennberg et al., 1993[72]	Prostate Disease PORT	Patients with experience of the disease	Focus group		Academia		Evidence informed patient choice	Research agenda published without detailing consumer contributions
Department of Health, 1995[60]	NHS R&D Asthma	Patients	Condition specific: asthma	UK, national	NHS R&D		Organisational change	Suggested problems needing R&D

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Tallon *et al.*, 2000[73]	Contract researchers	Patients with arthritis		UK, local	Academia		Evidence-informed patient choice	Consumer-identified priorities
Lane *et al.*, 1997;[76] Stone *et al.*, 1998[77]	Rehabilitation Engineering Research Center on Technology Evaluation and Transfer	'Experienced' technology users		USA	Commercial		Consumerism, partnership	Consumer priorities for criteria for evaluation
Batavia and Hammer, 1990[78]	Assistive devices engineering	All users of assistive technology devices on panels	Face-to-face: modified Delphi method		Commercial		Consumerism, partnership	Evaluation criteria incorporated by research programme
Griffin and Hauser, 1993[79]	Various face-to-face multiple	Individual product users					Consumerism, partnership	Evidence about methods for involving consumers
Brienza *et al.*, 1995[75]	Wheelchair engineering	3 out of 7 in the group were individual wheelchair users			Commercial		Consumerism, partnership	5 priorities set
D.3 Face-to-face encounters on a large scale								
Joss and Durant, 1995[80]	Various authorities	Members of the public					Participatory democracy	Few research topics identified
D.4 Combining face-to-face and written consultations								
Dalziel and Fulop, 2000[74] *Case investigated in more depth for UK episodes (see Chapter 5)*	*NHS R&D SDO*	*Consumer groups, patients and carers*	*Service delivery*	*UK, national*	*NHS R&D*		*'Listening'*	*Research agenda published without detailing consumer contributions*

Type E Responding to consumer groups with collaborations

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
E.1 Teamwork								
Cohen et al., 1999[81]	Homeless research programme in New York	Advocates and individual homeless people	Condition specific: homelessness	USA, local	Academia		Equal partnership	Record of client and staff research preferences
E.2 Multi-level participation designed in partnership with consumers								
The National Breast Cancer Coalition, 1994[84] and undated[85]	Breast cancer	NBCC in USA	Condition specific: breast cancer	USA, national	Government programme		Social action	Consumers secured extra funding for breast cancer research; National Action plan – aim to include consumers at every level of the decision-making processes
Rich et al., 1998[86]	Department of Defense Breast Cancer Research	Grassroots breast cancer organisations nation-wide		USA, national	Government programme		Organisational change	Human dimensions of breast cancer considered in funding decisions
California Breast Cancer Organization[83]	California Breast Cancer Organisation	Breast cancer survivors and related organisation advocates		USA, regional			Social action	Consumers as one-third of membership of Breast Cancer Research Council – enshrined in law

| Author(s) | Participants | | Research focus | Organisational setting | | Consumer involvement | | |
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Parboosingh et al., 1997[82]	Canadian Breast Cancer Initiative	Breast cancer survivors and their families					Participatory research approach	Survivor-driven national network of organisations and individuals established to, amongst other aims, increase openness and accountability in the research process
E.3 Consumer activism leading to organisational change and multilevel participation								
National Breast Cancer Centre, 1998[58]		NBCC in Australia	Breast cancer	Australia, national			Ethos: consumer involvement throughout programme	Research agenda published without detailing consumer contributions
Institute of Medicine, undated[67]	NIH	Patients/their families and advocacy					Organisational change	Recommendations on processes for involvement and funding
E.4 Community-based research								
Rice et al., 1994[88]	Contract social scientists	Residential community	Accident prevention	UK, local	Academia		Social action	Consumers identified issues and 'commissioned' researchers to do project
Dunbar, 1991[89]	Physicians	HIV activists	HIV			Prior activist experience	Social action	Community Research Initiative – one idea to design clinical trials with patient input

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Campbell, 1995;[90] Sherr, 1995[91]		UK Coalition of People Living with HIV/AIDS	Collaborating with range of professional partners – HEA, Royal Free Hospital to set up team working on issue	Partnership (implicit)	Research project		Outcome of lobbying on suicide issues	Research project
Renfrew and McCandish, 1992[92]	National perinatal epidemiology unit	National consumer group: NCT	Breastfeeding	UK, national	Academia			Completed randomised controlled trial, shared learning
Maher, 1995;[93] Bates and Evans, 1995[94]	Maher committee	National consumer group: RAGE	Committee membership		Research with patient involvement			Independent researcher's review of interaction

continued

Type F Responding to consumer action with consultation

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
Declercq, 1998[10]	Maternity care	National groups and individuals	Condition specific: pregnancy and childbirth	UK, national	Government enquiry		Representational democracy and social action	Consumers putting maternity care reform on to government agenda. Led to Department of Health Expert Maternity Group – Changing Childbirth Report
Roberts, 1999[95]	Royal Commission for new reproductive technologies, Canadian Government	Coalition of women	Reproductive technologies	Canada, national	Government body		Social action	Framework of R&D programme, but no analysis of the identified topics

Type G Responding to consumer action with research

| Author(s) | Participants | | Research focus | Organisational setting | | Consumer involvement | | |
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
G.1 Provoking research about patients' views								
Daugherty *et al.*, 1997[96]	Clinical cancer department	Patient	Cancer	USA, local	Hospital			Changed attitudes in associated research project
Butler and Wadman, 1997[97]	Cloning	General public	Cloning	International	Market research		Social action	Led to US- and EU-commissioned reviews on the ethics of cloning research
Aldous *et al.*, 1999;[98] Balls, 1999[99]	Cloning	General public	Cloning	UK, national	Market research			Controversy and publicity
G.2 Research matching consumers' priorities								
Colquhoun and Bunda, 1981;[100] Stevens *et al.*, 1995[102]	Clinical research: hyperactivity	Mothers of hyperactive children	Consumer-led research				Collective social action	Consumer research and subsequent professional research
Newburn, 1990;[103] MacArthur *et al.*, 1990;[104] Kitzinger, 1987;[105] National Research Register, 2001[106]	NHS R&D Mother and Child Health	National consumer group	Childbirth	UK, national	NHS R&D	History of campaigning and research experience	Collective social action	Consumer priority on national research agenda and commissioned research project
McCoy *et al.*, 1992;[107] Gibbs, 1982[108]	State Department of Health and Rehabilitative Services	Women in the local community	Lobbying				Collective social action	Epidemiological study

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
G.3 Research contradicting consumers' priorities								
Age Concern England, 1996;[109] Hendry and Entwistle, 1996[110]	UK Department of Health	Age Concern	Lobbying					Controversy and publicity
Horton Taylor *et al.*; 1996;[111] Age Concern England, undated[112]								
Age Concern England, 1995[113] and undated[114]								
Age Concern England, 1995[115]								

Type H Consumer-led research programme

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
H.1 Consumer calls for research								
Hanson, 1985[116]		National consumer group	Multiple sclerosis	UK, national	Consumer group	History of campaigning and research experience	Social action	Article by consumer – national press publicity
Harrington, 1992[117]		HIV activists	AIDS vaccine		Consumer activist		Social action	Consumer identified research topic – scientific press publicity
Schopler, 1996[118]		National consumer group	Autism	US, national	Consumer group		Social action	Comparison of consumer group priorities with national research programme
Fise, 1992[119]		National consumer federation	Indoor air pollution	US, national	Consumer group		Social action	Consumer identified research topic – press publicity
Hirschfield *et al.*, 1997[120]		Consumer groups and members of the public	Depression	US, national	Consumer group	Consumer-led consensus conference with professionals	Social action	Identified research priorities

Author(s)	Participants		Research focus	Organisational setting		Consumer involvement		
	Research programme	Consumer group(s)		Geographical scope	Institutional setting	Resources/ experience	Theoretical underpinning	Output
H.2 Consumer-controlled research								
The Mental Health Foundation, 2000[129] *Case investigated in more depth for UK episodes (see Chapter 5)*	*Mental Health Foundation*	*Service users and those who have suffered mental distress*	*Condition specific: mental health*	*UK, national*	*Charity, self-help group*		*Empowerment Equal opportunities*	*3 research topics identified and prioritised*
Oliver, 1993[42] *Case investigated in more depth for UK episodes (see chapter 5)*	*NCT*	*Maternity service users/NCT members*	*Condition specific: pregnancy and childbirth*	*UK, national*	*Consumer group*		*Social action*	*15 topics and 5 priorities*

Health Technology Assessment Programme

Prioritisation Strategy Group

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We look forward to hearing from you.