
Health Research: What's in it for consumers?

Report of the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme

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EXECUTIVE SUMMARY AND RECOMMENDATIONS

This report contains:

- a brief explanation of the NHS Research and Development Programme
- some examples of how consumers have been involved in the NHS Research and Development Programme
- historical background and analysis of consumer involvement in the NHS Research and Development Programme, from its inception in 1991 until 1997
- information about the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme - terms of reference, aims and values, an outline of the reasons why the Advisory Group was established, and work to date
- an examination of the barriers to further consumer involvement in the NHS Research and Development Programme, and suggestions about how these might be overcome
- the Advisory Group's plans for its second year of work
- recommendations made to the Central Research and Development Committee and to the Director of Research and Development

The recommendations made by the Advisory Group to the Central Research and Development Committee and to the Director of Research and Development were approved by the Central Research and Development Committee in October. These recommendations are as follows:

1. Approval of the Advisory Group's plans for the coming year (see section 7).
2. Involvement of the Advisory Group in the development of the revised NHS Research and Development Strategy, in order to ensure that
 - there is a consumer perspective on health research
 - there is research on consumer views
 - and that the consumer perspective is included in the development of outcome measures, to:
 - a) Endorse the developing joint work of the Advisory Group and the Health Technology Assessment Standing Group in promoting consumer involvement in the Health Technology Assessment Programme.
 - b) Ensure that the Advisory Group contributes to the development of the new Standing Groups looking at Service Delivery and Organisation and New and Emerging Technologies.

3. A requirement that when consumer membership is sought on advisory groups and committees within the NHS Research and Development Programme, at least two members will usually be invited to represent the consumer interest.
4. Availability of resources for consumers contributing to the NHS Research and Development Programme in the above ways, including funds for carer expenses.
5. Encouragement of the development of training to help consumers participate more fully in the research process, through support of programmes such as the Critical Appraisal Skills Programme (CASP).
6. Support for the publication of a consumer's guide to the NHS Research and Development Programme.
7. A requirement that future applications for Portfolio and Task Linked Funding within Budget One will include a question about whether and how consumer involvement is proposed within the research process.
8. Involvement of consumers at all stages of research and development within the NHS which is funded by non-commercial organisations, as laid out in the Statement of Partnership, and monitoring of this by the NHS Executive.
9. Within the monitoring process for Budget One, the identification and follow up of successful bids for Budget One funding where consumer involvement has been cited.
10. The appointment of a second consumer representative - who is able to represent the perspective of disease specific consumer organisations - to the Central Research and Development Committee.

PREFACE

A note about the language used in this report...

In this report we use the term '**consumer**' rather than 'user' or 'lay person' and we define consumers as patients and potential patients, carers, organisations representing 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. We recognise, however, that there is no single term used by

these groups of people to describe themselves. We also recognise that there are several definitions of the term 'consumer' (1).

By '**consumer involvement**', we mean the active involvement of consumers in the research process, rather than the use of consumers as the 'subjects' of research. This involvement might occur in any or all of the processes involved in research - setting the research agenda, commissioning research, undertaking research, interpreting research, and disseminating the results of research. We recognise that there have been many different and varied degrees of consumer involvement in health research and development.

The NHS defines research and development as:

- Work which is designed to provide **new knowledge**;
- the findings of which are potentially of value to those facing similar problems elsewhere (ie: it is **generalisable**); and
- the findings of which are planned to be open to critical examination and accessible to all who could benefit from them (i.e. **publicly disseminated**).

INTRODUCTION

The involvement of consumers in research changes the priorities for research. Simply having consumers present at research committee meetings can have a powerful effect - they remind researchers of the purpose of their work. Consumer involvement in maternity, HIV/AIDS and cancer research has resulted in particular emphasis being given to research on information and support (2). Yet with a few exceptions, consumers have had little say in how research is prioritised, undertaken and disseminated.

This is the first report from the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme to the Central Research and Development Committee.

The Standing Advisory Group (called the Advisory Group in this report) first met in April 1996 to advise the Central Research and Development Committee on the best ways to involve consumers in the NHS Research and Development Programme. The Advisory Group is a unique and dynamic initiative on the part of the Central Research and Development Committee and the Director of Research and Development - an initiative which is unparalleled across the rest of Whitehall. For the first time, the interests of consumers are represented at the very heart of NHS decision-making about research, through an advisory group whose members have first hand experience of bringing consumer concerns centre stage in research and development. The

Advisory Group is independent of the NHS Research and Development Programme and is resourced by a secretariat provided by the NHS Executive. It also has the remit to propose significant and innovative areas for research.

This first year hasn't been easy - nor would this be expected when a group is set up without an evidence base! This report describes our work to date, highlights the lessons that can be learned from it, and signposts future challenges.

It is important that such a unique initiative maintains some accountability to those with an interest in involving consumers in research. By distributing this report widely, we hope to begin a process of communication with those organisations and individuals whose interests we share.

Finally, the Advisory Group would like to acknowledge the work of Baroness Margaret Jay, Professor Sir Michael Peckham, Dr Iain Chalmers, and Professor John Swales and his team for making consumer involvement in health research a priority, and for pressing for the establishment of the Standing Advisory Group.

- Ruth Evans

Director, National Consumer Council and

Chair, Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme

I. WHAT IS THE NHS RESEARCH AND DEVELOPMENT PROGRAMME?

1.1. The NHS Research and Development Programme is an initiative which developed from the NHS Research and Development Strategy, in order to put the Strategy's objectives into practice. The Strategy itself was established in 1991, following the publication of a report by the House of Lords Select Committee on Science and Technology which highlighted the fact that the NHS lacked a mechanism to identify its research needs. The Strategy was developed by the NHS's first Director of Research and Development, Professor Sir Michael Peckham, and updated in 1993.

1.2. It aims to maximise the benefits for health of science and technology, and to apply research rigour to the problems confronting the NHS, public health and social services. Some of the Strategy's objectives are to contribute to the health and well-being of the population through the conduct and application of relevant, high quality research and development; to improve the scope, relevance and quality of research and development to inform policy and practice in health and social care; and to facilitate the development of a knowledge-based NHS and encourage an evaluative culture within it (3).

1.3. The Central Research and Development Committee (CRDC) was set up in 1991 to advise on the strategic direction of Research and Development in the NHS. The Central Research and Development Committee is a non-representational body of experts with different backgrounds and experience in the fields of research and service delivery. Membership includes people from disciplines such as medicine, nursing, research, health service management, health economics, social services and consumer organisations.

1.4. A central aim of the Central Research and Development Committee is to systematically identify and prioritise the research needs of the NHS. To date, the Central Research and Development Committee has used two approaches to identify research and development priorities:

- **A series of time limited Advisory Groups in areas of key importance to the NHS.** These have focused on areas such as mother and child health, physical and complex disabilities, asthma, cancer, and the interface between primary and secondary care.
- **A national Standing Group, with six advisory panels, which works annually to identify NHS needs for health technology assessment.** This is called the Health Technology Assessment (HTA) Programme. (Health technologies are methods of promoting health, preventing and treating disease and improving rehabilitation and long term care. They include the use of pharmaceuticals, health care procedures and settings of care.) (4)

1.5. In January 1997 the Central Research and Development Committee agreed to establish three broad-based structures to replace these two approaches. The new structures will be in place by 1998, and will cover:

- **Health technology assessment**

This will continue to ask the questions: Does the technology work? For whom? At what cost? How does it compare with other alternatives? It will focus on existing products and services.

- **Service Delivery and Organisation**

This will commission and promote the use of research evidence about how the organisation and delivery of services can be improved to increase the quality of patient care, ensure better patient outcomes, and contribute to improved population health. It is hoped that this will address some of the consumer priorities for research which were not easily addressed in the earlier arrangements.

- **Development of new and emerging technologies**

This will support work that leads to the development of new and improved clinical products and processes.

1.6. As a sub-group of the Central Research and Development Committee, the Advisory Group is central to the NHS Research and Development Programme. We aim to contribute to the development of these new structures (see paragraph 7.12).

Funding of Research and Development

1.7. The NHS is only one of a number of organisations to fund research and development on health in this country. Substantial sums are also spent by:

	£millions (estimated)
• The Department of Health	63
• The Medical Research Council	282
• Medical research charities	340
• The pharmaceutical industry	2000
• Higher education institutions	120

1.8. Since 1996, NHS Research and Development has been funded through a levy on all local health authorities in England. The money is used to fund research directly, and to support NHS providers who are undertaking research funded in other ways. This year (1997/98), the budget was around £425 million.

1.9. The overall budget is divided into two sections; £350million is awarded to providers of NHS services to meet costs incurred as a result of their involvement in research and development. This means that when those working in the NHS undertake research which is non-commercial and which is paid for by external funders (such as the Medical Research Council or medical research charities), they may receive payment for any extra costs they incur to the NHS as a result of undertaking this research. This might include costs for extra outpatient visits or an extra night as an inpatient, for example. This is called **Budget One**.

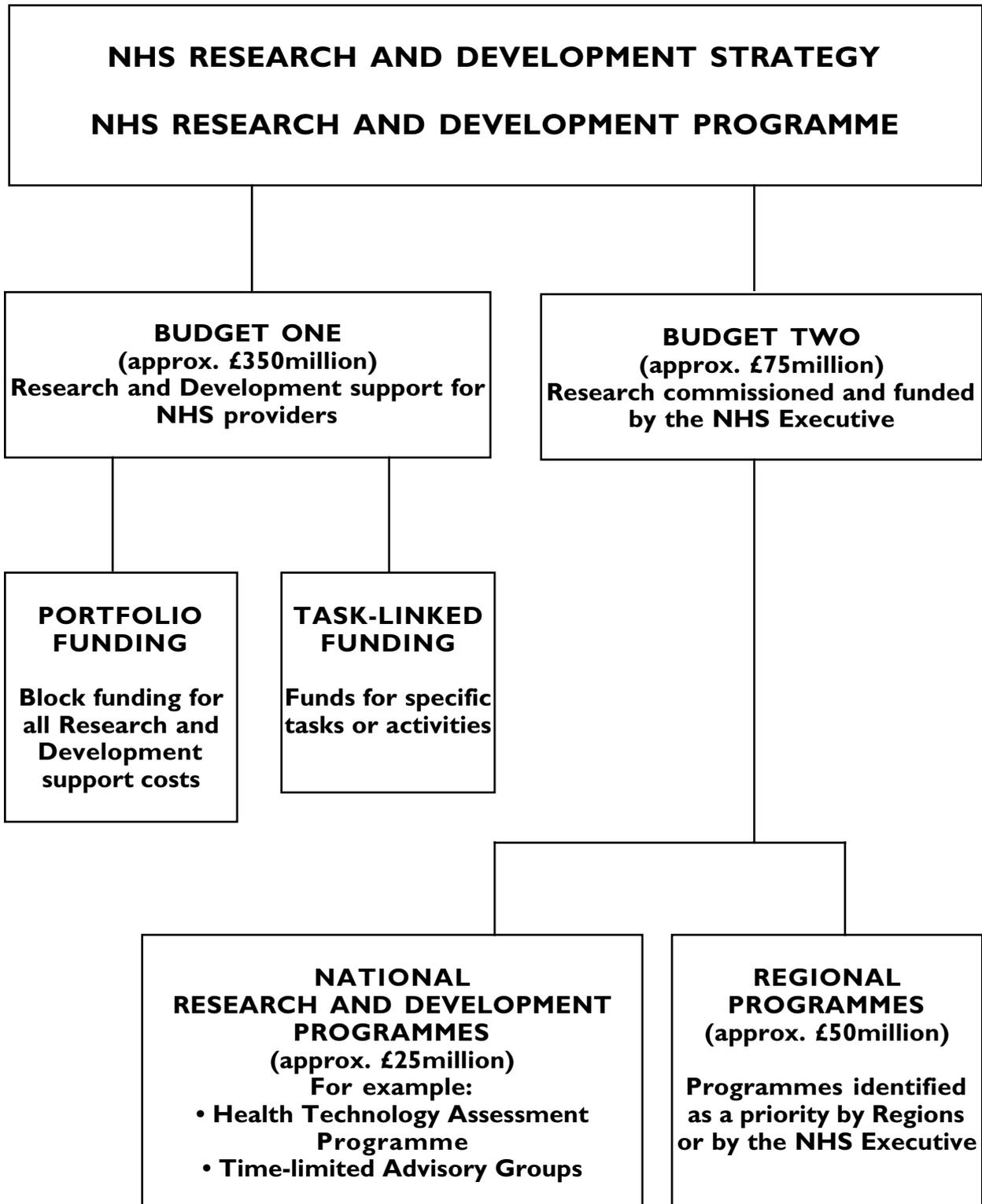
1.10. This year (1996/97), the way funds are allocated within Budget One has been changed. NHS providers have been invited to apply for funds to help them to meet the costs they incur as a result of their involvement in research and development - and there are now two different categories under which they can apply for funds. These are 'portfolio funding', which enables providers to apply for a block of funds to meet all of their research and development support costs, and 'task-linked funding', where funds are allocated for specific tasks or activities.

1.11. In April 1997, the NHS Executive published a Statement of Partnership, which specifies the circumstances under which the NHS will support non-commercial externally funded research and development by meeting the costs of any patient care associated with this (5). In April 1997 the Central Research and Development Committee agreed that this Statement of Partnership would require the funders to ensure that consumers are involved at all stages of the research process. The Advisory Group applauds this initiative.

1.12. The remaining £75million of the NHS Research and Development budget - **Budget Two** - is used when the NHS Executive identifies particular research and development needs that can be best met by its directly commissioning activity on behalf of the NHS as a whole. These needs are usually for specific research and development projects or programmes to address significant gaps in the evidence base for the NHS's work. About £25million of this budget is spent on national programmes, such as the Health Technology Assessment Programme. The remaining £50million is spent through Regional Offices.

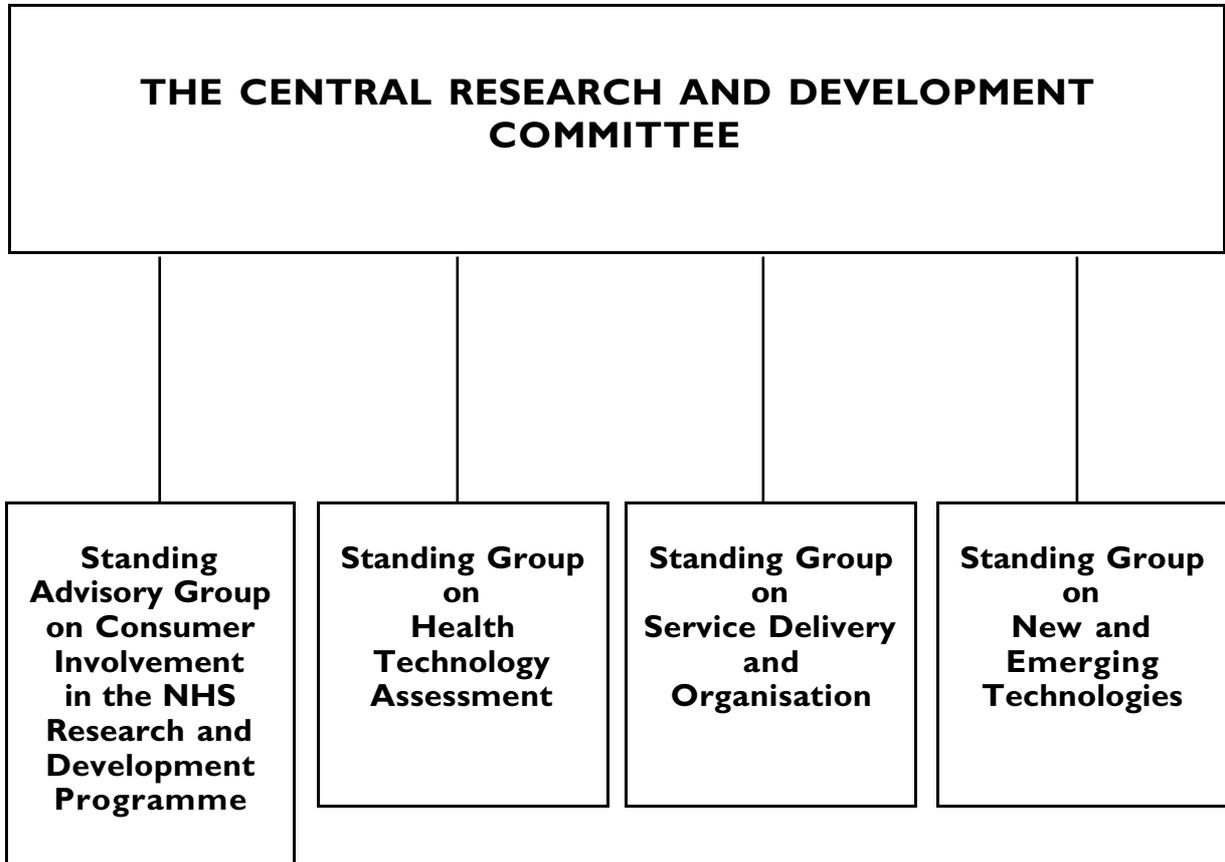
1.13. A diagram showing the structure of the NHS Research and Development Programme is shown on the next page.

THE STRUCTURE OF THE NHS RESEARCH AND DEVELOPMENT PROGRAMME



The Central Research and Development Committee provides strategic advice on the programme as a whole - including Budget One and Budget Two.

**THE CENTRAL RESEARCH AND DEVELOPMENT COMMITTEE
AND ITS WORKING GROUPS**



2. HOW HAVE CONSUMERS BEEN INVOLVED IN THE NHS RESEARCH AND DEVELOPMENT PROGRAMME SO FAR?

2.1. Research which involves consumers has been funded by the NHS and by other bodies for some years. Examples of consumer involvement in the fields of HIV/AIDS, maternity and disability research, and in areas examining health needs assessment, service provision and social aspects of care are particularly common.

2.2. Consumers have helped researchers to identify important questions. It was the mother of a child with a particular chromosomal abnormality, for instance, who first asked whether a low level of a maternal serum protein might be a prenatal marker for this condition (6). Consumers have also undertaken research on service delivery. The National Cancer Alliance, for example, has investigated the extent to which cancer services take into account the views of consumers (7). And consumers have been involved in the development of guidelines. Consumers connected to the Lynda Jackson MacMillan Centre for Cancer Support and Information have been involved in the development of guidelines which has changed the way bad news is given to people with cancer (8).

2.3. One of Advisory Group's first priorities has been to ascertain the extent and scope of consumer involvement in the NHS Research and Development Programme. Research undertaken for the Advisory Group (9) has identified some consumer involvement at all stages of the research process - from setting the research agenda through to disseminating the results of research - both at national and regional levels within the NHS Research and Development Programme.

Consumer involvement in SETTING PRIORITIES for research within the NHS Research and Development Programme

2.4. The 1991 NHS Research and Development Strategy led to the establishment of a series of time-limited Advisory Groups to help to prioritise research areas, and attempts were made to involve and/or consult consumers in this prioritisation process. Some consumer organisations were consulted in writing, others by means of regional workshops.

2.5. The Mother and Child Health Advisory Group, for example, consulted 181 organisations to help set priorities for research. Seventy of these were consumer organisations, 32 of which responded with suggested priorities. The Asthma Advisory Group convened a workshop to provide an opportunity for dialogue between clinicians, managers, patients and researchers to identify topics for the Group to consider. The Physical and Complex Disabilities Advisory Group invited consumers' views on research and development priorities through Regional workshops.

And the Advisory Group on Methods Promoting the Implementation of Research Findings convened a meeting involving consumers to help set the research agenda.

2.6. It is not clear, however, that the most relevant groups were consulted within each of the areas covered by the Advisory Groups. For example, it appears that the mailing list used by the Consumer Affairs and Quality Section of the NHS Executive was not used, even though this has the most extensive list of voluntary organisations held within the Executive. Established databases held within the voluntary sector were also not used.

2.7. Furthermore, although some of the Advisory Groups involved consumers as members of the Groups, others chose not to involve consumers. Some felt that the clinicians on these Groups could act as proxies for patients. Others were reluctant to become involved in what they felt was tokenism, or believed that the pressure to produce results quickly meant that there would not be enough time for consumers to play an effective role. Some of those involved in the process were sceptical that consumer involvement would make a difference to the outcome, despite the growing body of research that shows how consumer involvement, particularly in maternity and childbirth, HIV/AIDS and cancer care, does make a difference to decisions about what is researched and how it is researched (10).

2.9. Between 1991 and 1996, The Health Technology Assessment Programme (a Standing Group with 6 advisory panels) did not involve consumers in their panel meetings. However, there is now a commitment to involve consumers, and work has already begun in partnership with the Advisory Group to look at how this might best be put into practice (see paragraph 7.11).

Regional initiatives

2.10. Some regions have involved consumers in setting the research agenda for regional Research and Development Programmes. For example, in 1996 the North Thames Region commissioned the College of Health to undertake a piece of qualitative research on consumer and voluntary sector priorities for research and development. Sadly, none of the priorities identified within this research were adopted by North Thames.

2.11. The Wessex HIV and Sexual Health Research and Development Taskforce invited people without experience of research to submit project ideas which could be developed with the support of the Taskforce. A two day workshop was offered to shortlisted candidates to help them clarify their aims and objectives and to consider research methods. As a result, the sexual health, HIV transmission and health awareness of new age travellers is currently being investigated by a team of new age travellers, supported by voluntary sector workers and academics.

Consumer involvement in CONDUCTING RESEARCH funded by the NHS Research and Development Programme

2.13. Some consumer organisations have made successful bids for funds from the NHS Research and Development Programme to undertake research, both independently and in partnership with academic or health bodies. For example, the National Cancer Alliance secured funding to investigate the extent to which cancer services take into account the views of cancer patients, their families and carers, as well as those of health professionals.

2.14. The National Perinatal Epidemiology Unit has close links with consumer organisations in maternity and child health. Annual meetings bring together a range of consumers and researchers to discuss planned and ongoing trials.

2.15. Some NHS regions have been particularly keen to encourage consumers to bid for funds to undertake research. The Director of Consumer Affairs for North East Thames, for example, introduced academics and consumers to each other to build a collaborative research team. This involved the National Childbirth Trust, North Essex Health Authority, Mid Essex Community Health Council and the University of North London. Their research explored women's expectations and experience of choice during pregnancy, childbirth and early parenthood.

2.16. Consumers are also involved in preparing systematic reviews of evidence of effectiveness. The Cochrane Collaboration has a Consumer Network to attract and support world-wide consumer contributions to the preparation and use of systematic reviews. To date, consumers have been involved in planning reviews, commenting on review protocols, and preparing and maintaining systematic reviews themselves.

Consumer involvement in DISSEMINATING THE RESULTS OF RESEARCH funded by the NHS Research and Development Programme

2.17. One of the objectives of the NHS Research and Development Strategy is "to ensure that the benefits of research are systematically and effectively put into practice" (11). Consumers are actively involved in disseminating research findings. Some consumer organisations produce specialist newsletters for staff and volunteers summarising relevant research. Others are active in ensuring that research findings are put into practice by putting pressure on service providers and by being involved in the development of guidelines and protocols.

2.18. The NHS Executive, as part of its Patient Partnership Strategy, is now funding a national Centre for Health Information Quality. The Centre aims to promote the production of high quality information for patients, which is based on the best research evidence.

2.19. It is clear that consumers have been involved - albeit sporadically - in the NHS Research and Development Programme at all stages of the research process. However, the absence of a formal structure for securing and supporting consumer involvement means that experience and knowledge have not been shared effectively, and that efforts to involve consumers in research and development have been inhibited.

3. HOW FAR HAVE WE COME?

3.1. The 1991 Research for Health Strategy included a commitment to involving consumers at all stages of the research process. The impetus for this largely came from the Director of Research and Development at that time, Professor Sir Michael Peckham. However, there was no clear statement about how this would, or could, be put into practice.

3.2. In 1992 Baroness Jay, who was then a member of the Central Research and Development Committee, was asked to chair an ad-hoc group to address consumer issues within the NHS Research and Development Strategy. The group met once, and agreed to commission three reports. The first two of these were on consumer issues outside the NHS (undertaken by the Consumers' Association) and involving consumers in research (undertaken by Leonie Allday). Professor Mildred Blaxter was commissioned to produce the third report - a discussion paper summarising the literature and methods of research on consumer issues within the NHS which require research and development solutions. This report was completed in 1993, but was not published until 1995. The other two reports were not published, although Professor Blaxter used the report on involving consumers in research to inform her own paper.

3.3. At the same time, the regional director of NHS Research and Development at Trent Regional Office was asked to take responsibility for managing a national programme of research on consumer issues for the NHS Research and Development Programme. Trent initiated some work to ascertain what was already happening in this area within the regions, but were then asked by the NHS Executive to stop work, pending a workshop which was being planned at national level to address the research issues raised in the Blaxter report.

3.4. This workshop was held in October 1993. Participants were asked to consider how research and development could help to clarify the issues raised by Professor Blaxter and provide a

framework to explore them further. A report of the workshop, along with the Blaxter report (and a foreword by Professor Sir Michael Peckham) was published in August 1995 under the title 'Consumers and Research in the NHS' (12).

3.5. It is not clear why there was such a delay in publishing the Blaxter report, or indeed why little seems to have been done to promote the involvement of consumers in the NHS Research and Development Programme between 1991 and 1994, despite the commitment of a number of key individuals. A number of possible reasons have been suggested (13). These include a lack of commitment; a lack of knowledge about what involving consumers would mean in practice; the absence of a clear action plan; and the considerable organisational changes taking place in the NHS as a whole. It would perhaps be fair to say that there was genuine commitment in some quarters to involving consumers, but a lack of organisational infrastructure and the appropriate leadership to make it happen.

3.6. In October 1994 the Central Research and Development Committee agreed to set up a group to 'monitor and advise on consumer involvement in the NHS Research and Development Programme.' It was also agreed that a 'time-limited Advisory Group should be established to identify research and development priorities for the NHS on cost-effective methods for obtaining and using consumer views in decisions about the provision of health care.' This led to the establishment of the present Advisory Group in April 1996. Again, the reason for the delay between the decision to set up a group and its first meeting are not clear.

3.7. Although there were delays at every stage of this initiative, some activity was taking place elsewhere in the NHS, at a national level, on the organisation and delivery of services. A Patient Partnership Steering Group was set up, leading to the development of the Patient Partnership Strategy in 1996 (14), and the Clinical Outcomes Group set up a Patients' Sub-Group. This Sub-Group has produced a number of reports on involving consumers in clinical audit and outcomes.

4. WHAT IS THE STANDING ADVISORY GROUP?

4.1. The Advisory Group met for the first time in April 1996. Its members have first hand experience in involving consumers in health research and come from a wide range of disciplines. They include consumer advocates, researchers, clinicians, health information specialists, and health and social services managers. A list of members is attached as Appendix Two.

4.2. This Advisory Group is unique within the NHS Research and Development Programme. It is supported by the Research and Development Division through the provision of a Secretariat, and

has access to resources to commission research within its terms of reference. The Advisory Group also has a part-time scientific secretary, who assists in taking the work forward.

4.3. The Advisory Group has two sub-groups. One focuses on ways to ensure consumer involvement in setting the research agenda, and in designing and commissioning research. The other investigates ways of disseminating research based knowledge about treatments and other interventions to those most affected by these interventions - consumers.

Aims and values

4.4. The Advisory Group aims to ensure that consumer involvement in the NHS Research and Development Programme improves the way that research is prioritised, commissioned and disseminated. The Advisory Group identified the following principles to guide its work:

- consumer involvement will result in research that is more relevant and reliable, and more likely to be used
- consumer values and views are central to the concept of health and quality of life, to the relevance of outcome measures and to decisions about health care
- consumers often know best about their own individual health
- consumers, as stakeholders in the NHS, have a right to be involved in decisions about health care
- there should be mutual respect between consumers and professionals, for their respective contributions to health and health care
- decision makers and professionals involved in the NHS should seek to ensure that consumers are treated fairly and in accordance with their individual needs.

Initial work commissioned by the Advisory Group

4.5. The Advisory Group began by commissioning two background papers to help inform recommendations to the Central Research and Development Committee. The first investigated the history of consumer involvement in the NHS Research and Development Programme (15). The second examined examples of consumer involvement in health research, both within and beyond the NHS Research and Development Programme, and asked a number of consumer organisations for their views about the NHS Research and Development Programme (16).

5. WHAT STOPS CONSUMERS GETTING MORE INVOLVED?

5.1. The research undertaken on behalf of the Advisory Group has identified a number of barriers to the increased involvement of consumers in research(16). It is interesting to note that these barriers are similar to those identified in research carried out on behalf of the Patient Sub-Group of the Clinical Outcomes Group (17). Some of these barriers are perceived - others are real.

5.2. One of the perceived barriers identified by both consumers and professionals is a concern about representativeness. Some professionals interviewed on behalf of the Advisory Group (18) were concerned that one consumer may not be able to represent the views of all consumers in a particular area. Sometimes, concern about 'tokenism' and about the perceived danger of involving an 'unrepresentative' consumer meant that no consumers were involved in the prioritisation or research process. Many consumer organisations have observed that similar concerns are not noted when one clinician or academic is asked to 'represent' his or her area of expertise.

5.3. Some consumer groups interviewed on behalf of the Advisory Group felt that the written consultation exercises undertaken in connection with the various research and development programmes were problematic, because of the sheer volume and complexity of information which was required from them (18). For example, letters sent to consumer organisations regarding the Health Technology Assessment Programme in 1996 asked them to explain why the health problem was important to the NHS; to suggest solutions to the problem and include key references to justify this; and to state whether there was already any on-going assessment in this area and whether the timing of the assessment was crucial. Thus, respondents to the consultations needed to be either very well informed or willing to respond in ignorance and in hope that their suggestions might be developed further. Reports to the Advisory Groups suggest that this approach had mixed success. The Advisory Group notes that the papers sent out on priorities for the Health Technology Assessment Programme in 1997 are much easier for consumers to complete.

5.4. The timescale set for consultations on priorities for research meant that some consumer organisations were unable to consult with their members before responding or contributing. Other consumer organisations were concerned about the complexity of language used in consultation documents, as well as the volume of paper. Lack of continuity of NHS staff, who were seen as repeatedly asking the same questions, was also seen as a barrier. Some consumer organisations felt that there was a lack of guidance about how to respond to consultation exercises, and a lack of feedback if they did respond. This has led to cynicism amongst some consumer organisations about the willingness of research staff to listen, and to act on what they hear.

5.5. The committee structure, which is an integral part of the NHS Research and Development process, is seen by many consumers as an inhibiting or inappropriate setting for consumer

involvement. Consumers are perceived by others as lacking the specialist knowledge needed to take an active part in committees. Consumers who find themselves to be the single consumer representative on a research committee often find it very difficult to make their viewpoint known, and would appreciate peer support. They may also lack the resources to attend meetings - child care, for example, or funding for travel costs.

5.6. Consumer organisations are also unclear about how the NHS Research and Development Programme works and how they can best contribute. They may be unclear about the reasons for involving them in a particular initiative. Some consumer organisations feel that the process of making decisions about funding and priorities within the NHS Research and Development Programme lacks explicit criteria and openness.

5.7. The involvement of consumers may change the priorities for research. There is concern amongst some professionals that involving consumers in research may divert attention away from what they - the professionals - see as the most urgent problems to be addressed. Professionals may be less likely to involve consumers in the research process if they feel priorities will not coincide.

5.8. Consumer organisations are more likely to apply for funds to undertake qualitative research. However, there is a widespread perception that qualitative research is less likely to be funded within the NHS Research and Development Programme.

5.9. There are, then, a number of barriers which need to be overcome if consumers are to become more effectively involved in the NHS Research and Development Programme. Some suggestions about how this might be achieved, based on the background papers commissioned by the Advisory Group, are outlined below.

6. HOW DO WE OVERCOME THE BARRIERS ?

6.1. The background papers prepared for the Advisory Group identified examples of successful consumer involvement. Features of such initiatives seen as instrumental in their success include:

- training to help consumers understand and use research reports. Some of this training was provided by the Oxford Institute of Health Science's Critical Appraisal Skills Programme (CASP). Some projects also offered training to professionals where necessary.
- prior thought to the aims of the project, the task to be addressed, the skills required and the people best able to fulfil them.

- clarity about the reasons for involving consumers and about their role within a group or committee, thus helping to resolve some of the issues about representativeness.
- potential barriers identified and overcome in advance, particularly time restrictions which could prevent consumers consulting with others and considering their responses.
- time for consumers to understand the history, organisation and aims of the research, and for researchers to understand the experiences, organisation and aims of the consumers.
- adequate resources to enable full participation, including travel or childminding expenses, wheelchair accessible meeting rooms, etc.
- avoidance of consumers becoming a ‘lone voice’ on research committees.
- continuity in staff supporting the project.
- evaluation of the process of involving consumers in research and implementation of lessons learned.

These factors demonstrate how some of the barriers to consumer involvement can be overcome.

7. WHERE DO WE GO FROM HERE?

7.1. The Advisory Group has now completed its first term of reference, which is to review the ways in which consumer views have been addressed in all stages of the NHS Research and Development Programme to date. We have also begun to identify themes for further exploration. These are:

Advice to the Central Research and Development Committee on priorities regarding consumer involvement in research

7.2. Having considered the background to consumer involvement in the NHS Research and Development Programme, the Advisory Group has now commissioned three research projects. These are:

- a census of health research projects in which consumers have been involved
- a census of health research projects in which black and ethnic minority consumers have been involved
- a systematic review of the similarities and differences between consumer and professional priorities for health research

7.3. This will be the first time that information of this kind will have been collected together about these three key areas. The research projects are described in more detail below.

- **A census of health research projects involving consumers**

7.4. This research project will involve the compilation of a census of published and unpublished health research which has actively involved consumers in the various stages of the research process, from selection and prioritisation of research topics through to the dissemination of results. The Advisory Group will use the findings of this project to inform its recommendations to the Central Research and Development Committee, and as a resource which can be accessed for future research.

- **A census of health research projects in which black and ethnic minority consumers have been involved**

7.5. Both the Advisory Group and the Central Research and Development Committee have recognised that there is a need for information and recommendations about the involvement of people from black and ethnic minority communities in health research. The Advisory Group has therefore agreed to commission a research project which will complement the census outlined above. This project will involve the compilation of a census of published and unpublished health research in which black and ethnic minority consumers have been actively involved in the research process. Again, this research will be used to inform future recommendations of the Advisory Group to the Central Research and Development Committee, and as a resource for future research.

- **A systematic review of the similarities and differences between consumer and professional priorities for health research**

7.6. Although some researchers believe that consumer input to the research process results in better research (19), others believe that the views of health care professionals and researchers can be effective surrogates for consumer views (20). During the 1990's, there has been a growing interest in investigating matches and mismatches between the views of those using health services and the views of health care providers and health researchers about their priorities for health care and health research. In addition, there has been some research assessing the extent to which the views of members of advocacy groups - and the positions adopted by these groups - reflect the views of representative samples of people living with particular health problems. Although there have been some important exceptions, many studies identified on behalf of the Advisory Group have found important mismatches between professional and consumer views (21). If these studies are representative of this body of evidence, it provides grounds for exploring how to involve consumers in setting research priorities and designing research, with the intention of reducing the mismatches which exist. The Advisory Group is therefore commissioning a systematic review of the existing research evidence in this area.

7.7. These research projects were advertised in September 1997, and researchers have now been appointed. During the coming year, the Advisory Group will be receiving and discussing reports on these research projects, and will use them to inform recommendations to the Central Research and Development Committee in 1998, and to propose a commissioned programme for research.

Monitoring arrangements for consumer involvement in the work of the Central Research and Development Committee

Research for Health

7.8. A revised policy document setting out the objectives and principles of the NHS Research and Development Strategy will be developed over the next year. The Advisory Group wishes to contribute to this process to ensure that the involvement of consumers at all stages of the research and development process is seen as a priority.

National Research and Development programme - Budget One

7.9. This year, the way funds are allocated within Budget One has been changed. A Statement of Partnership will require non-commercial external funders of research and development taking place within the NHS to ensure that consumers are involved at all stages of the research process. (see paragraphs 1.9 to 1.11). Once decisions regarding the allocation of funding within this budget have been agreed, the Advisory Group will be discussing how it might offer assistance to the Central Research and Development Committee in monitoring compliance with this element of the Statement of Partnership, and whether there are ways of identifying and following up those successful bids where consumer involvement has been cited.

7.10. The Advisory Group also wishes to ensure that the application forms for next year's Task-Linked Funding and for Portfolio Funding in four years' time include a question regarding consumer involvement in research projects. We believe that these steps will signal the importance attached to the involvement of consumers in the research process by the NHS.

National Research and Development programme - Budget Two

7.11. The Advisory Group has already undertaken some positive work with colleagues in the Health Technology Assessment Programme. Advisory Group members have attended Health Technology Assessment advisory panel meetings as observers, and have made a contribution to a Health Technology Assessment vignette outlining research needs for involving consumers in identifying and prioritising possible topics for Health Technology Assessment. The Advisory Group is now working with the Health Technology Assessment Panels to identify ways in which consumers can be involved at all stages in the Health Technology Assessment process.

7.12. The Advisory Group wishes to ensure that there is consumer involvement in the two new Advisory Groups established by the Central Research and Development Committee (looking at Service Delivery and Organisation and New and Emerging Technologies) by working closely with those involved in their development.

A conference on consumer involvement in health research

7.13. The Advisory Group has organised a conference on consumer involvement in health research. This will be held on 28th January 1998 at Kensington Town Hall in London. The aim of the conference is to gather and exchange information about good practice, and to inform the future priorities of the Advisory Group. The conference will also be used to raise the profile of the Advisory Group and therefore encourage commitment by the NHS and others to further consumer involvement in the NHS Research and Development Programme.

A Consumer's Guide to the NHS Research and Development Programme

7.14. The Advisory Group plans to produce a simple introduction to the NHS Research and Development Programme for use by consumer organisations and individual consumers with an interest in health research. This will include a clear description of the new funding arrangements for research and development, and of the new structures which will help to inform funding priorities. A draft of this guide will be presented to the Central Research and Development Committee for its comments.

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APPENDIX ONE

The Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme

Our terms of reference

The Advisory Group's terms of reference are:

1. To review ways in which consumer views have been addressed in all stages of the NHS Research and Development Programme to the end of December 1996.
2. On the basis of the information gained in this review, to make recommendations on how consumer involvement could be enhanced in each stage of the Research and Development process. This would include:
 - advising on priorities to be addressed in new research within the NHS Research and Development Programme
 - agreeing the methodologies to be used to address these priorities
 - commissioning and managing the conduct of the research
 - reporting on completed research
 - in association with the NHS Patient Partnership Initiative, disseminating and using the results of research to help consumers reach informed decisions about their own clinical treatment.
3. To monitor arrangements for consumer involvement in the wider work of the Central Research and Development Committee and its sub-committees.
4. To advise on priorities for a programme of commissioned research into consumers' involvement in the NHS Research and Development Programme.
5. To report regularly to the Central Research and Development Committee.

APPENDIX TWO

The Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme

Our membership

Chair:

Ruth Evans - Director, National Consumer Council

Vice Chair:

Iain Chalmers - Director, UK Cochrane Centre

Annie Bartlett - Senior Lecturer in Forensic Psychiatry, St George's Hospital Medical School

Carol Baxter - Lecturer in Health Studies, University of Central Lancashire

Jane Bradburn (from February 1997) - Lynda Jackson MacMillan Centre for Cancer Support and Information, Mount Vernon Hospital

Harry Cayton - Director, Alzheimer's Disease Society (Chair of Conference Planning Sub-Group)

Chris Davies - Director of Social Services, Somerset County Council

Vikki Entwistle - Research Fellow, Centre for Reviews and Dissemination, University of York

Lesley Fallowfield (until January 1997) - Communication and Counselling Research Centre

Christina Funnell - European Editor, The Patients Network

Bob Gann - Director, Help for Health Trust (Chair of Dissemination Sub-Group)

Diana Garnham (from October 1997) - General Secretary, Association of Medical Research Charities

Valerie Harrison - Chief Executive, South Bedfordshire Community Healthcare NHS Trust (Chair of Tender Assessment Sub-Group)

Tony Hope - University Lecturer in Practice Skills (Ethics, Communication Skills and the Law), University of Oxford (Chair of Commissioning Sub-Group)

Debra Humphris - Senior Research Fellow, Health Care Evaluation Unit, St George's Hospital Medical School

Alistair Kent (from February 1997) - Director, Genetic Interest Group

Barbara Meredith - Senior Policy and Development Officer, National Consumer Council, and Chair, Patient Sub-Group, Clinical Outcomes Group

Ann Oakley (until March 1997) - Social Science Research Unit, Institute of Education, University of London

Sandy Oliver (until March 1997) - Social Science Research Unit, Institute of Education, University of London

Nick Partridge - Chief Executive, Terence Higgins Trust

Maggie Pearson (from October 1997) Regional Director of Research and Development, NHS Executive North West Regional Office

Jill Pitkeathley - Chief Executive, Carers National Association

Caroline Woodroffe (from February 1997)- Freelance Health Service Researcher

Observers:

Steve Jolliffe - Corporate Affairs Division, NHS Executive

Joan Box - Medical Research Council

Secretariat:

Bec Hanley - Scientific Secretary, Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme

Chris Bostock - Research and Development Division, NHS Executive

Lenora Clarke - Research and Development Division, NHS Executive

MORE INFORMATION

If you would like more information about the work of the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme, please contact:

Bec Hanley

Scientific Secretary

The Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme

PO Box 1629, Hassocks BN6 8EP

Telephone and Fax: 01273 841771