

Involvement works

The second report of the Standing Group
on Consumers in NHS Research

A note about the language used in this report

In this report we use the term “consumer” rather than “user” or “lay person”.

We define consumers as patients, 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 to describe themselves. We also recognise that there are many 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 “subjects” of research.

This involvement might occur at any stage in the research process - from setting the research agenda, to commissioning research, undertaking research, interpreting research and disseminating the results of research. We recognise that there are many different ways that consumers can be actively involved in research.

The NHS has defined “research and development” as work which is:

- designed to provide new knowledge;
- potentially of value to those facing similar problems elsewhere, and
- likely to be disseminated.

“Research and Development” is often referred to by the initials “R&D.”

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Foreword

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


Thus in 1996 I was pleased to hear of the establishment of a new group to promote the involvement of consumers in R&D in the NHS - the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme.

As a member of the Central Research and Development Committee of the NHS I welcomed the Standing Advisory Group's first report, entitled *Research: What's in it for Consumers?*, published in January 1998. It is a great pleasure for me to receive the Group's second report.

The Standing Group on Consumers in NHS Research, as this Group is now called, has undertaken an immense amount of work over this last year. Thanks are due to Ruth Evans and all of those involved in the Group for their time and expertise.

From this report you will see that consumers are playing an increasing role in research and development in the NHS at national, regional and local levels. We are beginning to see more clearly the positive impact that this involvement has at every stage of the research and development process.

I look forward to further reports from the Group.

A handwritten signature in black ink, reading "Malcolm Green". The signature is written in a cursive style. Below the signature is a horizontal line.

Malcolm Green
Acting Director of Research and Development

Executive summary

The Standing Group on Consumers in NHS Research was set up in 1996. Its aim: to ensure that consumer involvement in research & development improves the way that research is prioritised, commissioned, undertaken and disseminated.

This is the Group's second report. It describes work undertaken during the past year, and outlines our plans for the future.

In the past year the Group has:

- Commissioned three research projects:
 1. A database of health research projects which have actively involved consumers;
 2. A database of health research projects which have actively involved black and minority ethnic consumers; and
 3. A review of the similarities and the differences between consumer and professional priorities for research.
- Taken an active role in the pilot project to involve consumers in the Health Technology Assessment Programme in the NHS
- Successfully promoted the involvement of consumers in the Service Delivery and Organisation and the Health in Partnership Research Programmes

- Held an effective and oversubscribed conference on consumer involvement in health research, which was attended by nearly 400 people
- Produced a consumer's guide to research and development in the NHS (to be published in early 1999)

During the next year, the Group will focus on four key objectives:

- To classify the different types of consumer involvement in health research and promote awareness of this classification system
- To develop alliances that will enable us to promote greater consumer involvement in health research
- To empower consumers to become more involved in research & development in the NHS
- To monitor and evaluate the effects of consumer involvement in research and development in the NHS

The Group's long term goal is to ensure that consumers are involved as a matter of course in research & development in the NHS at national, regional and local levels.

1. Introduction

1.1. The Standing Group on Consumers in NHS Research (formerly called the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme) was set up by the Director of Research and Development in 1996. It aims to ensure that consumer involvement in research and development in the NHS improves the way that research is prioritised, commissioned, carried out and disseminated.

1.2. The Standing Group on Consumers in NHS Research (which will be referred to as “the Group” from now on in this report) presented its first report to the Central Research & Development Committee (CRDC) in October 1997 (2). It outlined work undertaken by the Group in its first eighteen months, including two research studies - a history of consumer involvement in the NHS Research & Development Programme to 1996, and a collection of examples of consumer involvement in health research.

1.3. This, our second report, outlines work undertaken by the Group between October 1997 and December 1998 and describes our plans for the next fifteen months (to March 2000). It also includes some examples of consumer involvement in research and development in the NHS, to illustrate the scope of activity in this area.

example ‘a’

NHS EXECUTIVE,
NORTHERN & YORKSHIRE REGION

The Regional R&D Directorate at Northern and Yorkshire is beginning a programme of consumer involvement in the planning of the Regional R&D Programme.

During 1998, a pilot project of consumer involvement in the identification of priorities for Regional R&D was conducted. Consumer organisations were asked through a questionnaire about their priorities for research, and community health councils in the region organised consultation through local network meetings and specially arranged focus groups.

The consumers involved in this project identified the following as priorities for research:

- Service delivery in general practice and community services, and the provision of patient information.
- The health needs of older people, people with chronic disease (such as asthma and arthritis), and people with mental health problems.
- Medical conditions - cancer, mental health and heart disease.

78% of the respondents thought that the public should be involved in identifying priorities for the regional R&D Programme. Their reasons for this included that they felt they know the issues and what is important locally, that they pay for the service, and that researchers and professionals may have different views/agendas from the general public.

The Northern and Yorkshire Region now requires that all applications for funding for research projects must include a statement of how consumers will be involved.

2. Why is it important to involve consumers in research and development in the NHS?

2.1. The Group believes that the involvement of consumers will lead to research which is more *relevant* to the needs of consumers (and therefore to the NHS as a whole), more *reliable*, and more *likely to be used*. If research reflects the needs and views of consumers, it is likely to produce results which can be implemented.

2.2. The involvement of consumers can change the priorities for research. At Mount Vernon Hospital in Middlesex, for example, researchers found that involving cancer patients in the design of a trial actually changed their original hypothesis.

2.3 The researchers had originally designed a protocol to address the problem of over-burdened outpatient clinics, hypothesising a shift to primary care as the answer. However, the women commenting on this study said that they did not realise that there was such a problem. They said that they generally had more confidence in their hospital consultant and suggested their own solutions (3). The result? Research priorities were changed in response to the women's contribution - the protocol was redesigned to look at making access to specialists easier.

2.4. We also know that the involvement of consumers can improve the quality of the research prioritisation process for everyone. This year, the Health Technology Assessment Programme set up a pilot project to involve consumers in its work. They aimed to assess the resources, skills and organisational changes needed to involve consumers in all aspects of the programme.

2.5. By involving consumers on panels prioritising research topics, they were able to identify the training needs of new panel members, establish appropriate training, and reconsider the way that peer review is undertaken. These changes improved the quality of the prioritisation process for everybody involved. (More information about

this pilot project is included in the example on page 7).

2.6. The involvement of consumers in research projects can change the way that research is undertaken. An example of this is provided by the Shaping Our Lives Project at the National Institute of Social Work. Shaping Our Lives is a consumer-led project and involves consumers fully at all levels. It has found that services need to develop an approach to provision based on user-defined objectives and outcomes. It now supports the users of community care services in defining and working towards the outcomes they want from these services.

2.7. A key objective of the project is to develop consumer perspectives on the debate about outcomes which until recently has been dominated by service providers (4).

2.8. The involvement of consumers in disseminating the results of research can have a substantial impact on its implementation. AIDS organisations, for instance, in addition to actively collaborating in the design of research studies, have also disseminated the results of research.

2.9. The National AIDS Manual, the Terence Higgins Trust and other organisations supporting people with HIV/AIDS all disseminate the results of research projects through publications and conferences, so that individuals with HIV/AIDS can ensure they receive care based on the latest research evidence. This dissemination of research also enables AIDS organisations on a local and national level to campaign to ensure that evidence based care is provided across the country.

3. About research and development in the NHS and how consumers are involved

3.1. The NHS Research & Development (R&D) Strategy aims to:

- co-ordinate research in the NHS and aim it at priority questions for the NHS, and
- ensure that the NHS is informed by knowledge about research findings, to maximise the effectiveness, efficiency and appropriateness of its work.

3.2. This year (1998/99), the NHS has a budget of around £423 million for research. Decisions about how this money should be spent are based on the needs of the NHS and those it serves. Money is spent at national and regional levels. More information about R&D in the NHS is contained in the Group's forthcoming publication - *Research & Development in the NHS - How can You Make a Difference?* (5)

3.3. In the Group's first report "Research, What's in it for Consumers?" (6) we outlined the history of consumer involvement in R&D in the NHS, and described how consumers had been involved to date. The Group has been pleased to note the continuing increase in the involvement of consumers in research, both within and beyond the NHS. Examples of this are featured through the case studies included in this report.

example 'b'

THE HEALTH TECHNOLOGY ASSESSMENT PROGRAMME

This year, the Health Technology Assessment (HTA) Programme - a key part of the NHS R&D Strategy - set up a pilot project to involve consumers in its work. They aimed to assess the resources, skills and organisational changes needed to involve consumers in all aspects of the Programme.

To do this, they identified opportunities and developed methods for consumer involvement in the five main tasks of the HTA Programme, which are:

1) identifying possible topics for HTA; 2) prioritising topics for HTA; 3) commissioning research; 4) monitoring research; and 5) communicating openly about the processes and products of the Programme.

The project began on 1 November 1997, with researcher Sandy Oliver working one day a week alongside staff at the National Co-ordinating Centre for Health Technology Assessment (NCCHTA).

In their report - *Needs and Feasibility Study for Developing Consumer Involvement in the NHS R&D Health Technology Assessment Programme* - they found that:

- The most fruitful way of identifying research questions that are important to consumers is to discuss it with them face to face and offer follow-up support.
- Consumers involved in the prioritisation process faced language barriers and needed a quiet apprenticeship, adequate time, better briefing, training and ongoing support. These problems were not unique to consumers but they felt them more acutely.
- Consumers who reviewed research proposals and reports found the reviewing forms inadequate and irrelevant to their contributions. Consumers tended to highlight issues about patients' views, social contexts, information and support needs, long term outcomes, and dissemination of research

findings to consumers. These issues were not addressed so much by professional referees, who tended to focus on more scientific and economic aspects of the work.

- Consumers expressed interest in both the processes and the products of the HTA Programme. Having heard about the HTA Programme, one consumer group is initiating its own trawl for research topics. Another group will use an HTA research report to write leaflets for patients. However, consumers do not always agree with the reports' methods or conclusions.
- Consumers made unique contributions to

the HTA Programme. Their involvement exposed processes which needed further thought and development.

The National Co-ordinating Centre for Health Technology Assessment (NCCHTA) responded positively, and consumer involvement benefited from the NCCHTA being comfortable with innovation, participative development and team learning.

The NHS Executive has decided to fund the NCCHTA to maintain and increase the role of consumers in the HTA Programme over the next few years.

4. The Standing Group on Consumers in NHS Research:

An advisory group on consumer involvement in research and development in the NHS

4.1. The Group was set up in 1996 by the Director of R&D. It is a sub-group of the Central Research & Development Committee (CRDC), which advises the Director of R&D on priority setting and how funds should be spent. The Group is also a key part of the NHS Patient Partnership Strategy.

4.2. The Group aims to ensure that consumer involvement in research and development in the NHS improves the way that research is prioritised, commissioned, undertaken and disseminated. The Group believes that consumer involvement will result in research that is more relevant and reliable, and more likely to be used. Our Terms of Reference are included in Appendix One.

4.3. Members of the Group come from a wide range of backgrounds - consumer organisations, the research community, the NHS, health information and social services. All have a commitment to and experience of involving of consumers in research. A list of our members is attached as Appendix Two.

4.4. The Group advises the NHS Executive, but is independent of it. It has access to a budget to commission research within its terms of reference. It is supported by the Research and Development Division of the NHS Executive through a secretariat and has a part time scientific secretary who helps the Group to undertake its work.

4.5. In February 1999 the Group established a new base at the Help for Health Trust in Winchester. This will ensure that those wishing to contact the Group for advice and information can do so through a permanent, well established institution. Additional staff will also be appointed to reflect and respond to the growing interest in this area.

5. The Group's work during 1997/98

5.1. The Group's first report outlined its priorities for 1997/98. Below is a report on our progress with these priorities.

Research Projects

5.2. Three research projects have been commissioned:

1. A database of health research projects in which consumers have been involved;
2. A database of health research projects in which black and minority ethnic consumers have been involved
3. A review of the similarities and differences between consumer and professional priorities for health research.

Work began on these research projects in January 1998. You'll find a brief summary of each of the projects in Section 6 of this report, which starts on page 11.

5.3. In addition to commissioning and managing the research projects described above, the Group undertook a number of activities to promote consumer involvement in R&D in the NHS at a national level:

The Health Technology Assessment Programme

5.4. The Group has been involved in a pilot project to involve consumers in the Health Technology Assessment (HTA) Programme (described in example 'b' on page 7).

5.5. Group members have been impressed and encouraged by the commitment of the staff at the National Co-ordinating Centre for HTA and of those involved in the HTA Programme to involve consumers, and by the work of those consumers who were involved in the pilot project.

The Service Delivery & Organisation Programme

5.6. The Group has worked to ensure that consumers are involved in the new national research programme focusing on Service Delivery & Organisation. Two members of the Group are also members of the new Steering Group for this research programme, and the programme director, Professor Maggie Pearson, is a member of the Group.

5.7. From information collected through the Group's research projects and at our conference, it is clear that consumers have a particular interest in research in this area. We commend the fact that those tendering to manage this new programme of work were asked to state within their tender how they would help to promote consumer involvement in the programme.

The Health in Partnership Research Programme

5.8. Modern, quality health services need to be informed by good evidence from research and development. Over the next four years, the Department of Health's Policy Research Programme will be funding a group of research studies to look at different ways in which consumers can have a say about decisions about health care. Research is needed to identify what "best practices" are in involving consumers in decision making. This will help to ensure that activities designed to consult and involve consumers in decisions about health care will in future be based on the best information available about what works well in which situation.

5.9. The Group has been actively involved in plans for this research programme, and has advised the Policy Research Programme on ways in which consumers can be involved in the research commissioning process.

The Statement of Partnership

5.10. In 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 in the NHS, by meeting the costs of patient care associated with this. This Statement of Partnership requires funders take into account the need to ensure the involvement of patients

or their representatives in the design and implementation of research and the dissemination of the results. The Group is considering how best to assist the Central Research & Development Committee in monitoring compliance with this part of the Statement.

A new research strategy for the NHS

5.11. The Group will be contributing to the new NHS R&D Strategy - *Research for Health and Social Care* - in order to ensure that consumer involvement in R&D in the NHS continues to be seen as a priority, and to encourage those undertaking R&D within the NHS and social services to actively involve consumers in their work.

5.12. In addition to the activities mentioned above, which promote consumer involvement in research and development in the NHS at a national level, the Group also undertook the following projects:

A conference on consumer involvement in health research

5.13. The Group organised a conference on consumer involvement in health research, which took place in January. Nearly four hundred people attended, and a further fifty were turned away due to lack of space. Consumers, researchers and those working in the NHS came together to share ideas and good practice. Response to the conference was extremely positive - almost everyone who completed evaluation forms felt they had learned a lot about consumer involvement in health research, and many people requested a further conference on this theme. A report of the conference - *Research: What's in it for me?* (7) was published in August.

A consumer's guide to Research and Development in the NHS

5.14. Designed to make R&D in the NHS more accessible to consumers, this guide will be published in April 1999. Based on the questions consumers said they would most like to see answered in such a guide, it defines research and development in the NHS, outlines why it is needed, and explains how research is funded, prioritised, commissioned and disseminated. It also describes how consumers can get involved in R&D in the NHS, and provides contacts for further information.

example 'c'

INVOLVING CONSUMERS IN THE DESIGN OF BREAST CANCER TRIALS

Consumers, researchers and clinicians worked together to design and monitor a national randomised trial of the use of hormone replacement therapy as a treatment for women experiencing menopausal symptoms with early stage breast cancer.

The Consumer Advisory Group for Clinical Trials (CAG-CT), together with the Patient Involvement Unit, Lynda Jackson-Macmillan Centre and with funding from the NHS R&D Programme on Cancer, developed a model for involving patients in the design of the trial through the use of focus groups.

The various stakeholders in the research, including representatives from each focus group, then met to determine and agree priority issues for consideration in the trial design.

Representatives from that meeting were responsible for monitoring the agreed action points and ensuring they were considered by clinicians in the design of the trial.

As the study progressed, it became evident that using accrual as a measurement was a gross simplification of the decision-making process in taking part in a trial.

It highlighted the importance of adequate information for patients upon which to base decisions. As a result, a booklet for patients - *Breast Cancer, Hormones and HRT* - was produced by the Patient Involvement Unit.

6. The Group's research projects

6.1 This section outlines the three research projects commissioned by the Group. Work began on them in January 1998.

1. A database of health research projects in which consumers have been involved

6.2. Although there is a body of research documenting consumer involvement in the various stages of health research, it has often been difficult for consumers wishing to become involved in research - and for researchers wishing to involve consumers - to learn from the experience of others. The Group therefore agreed to commission a database of published and unpublished research which has involved consumers, in order to inform the work of the Group, and to provide consumers and researchers with examples from which they might learn. This project was undertaken by Roy Carr-Hill and colleagues at the Centre for Health Economics at York University (8).

6.3. The researchers identified over four hundred research projects in which consumers have been actively involved. Agencies that are involving consumers in research include voluntary organisations and self help groups, community health councils, primary care practices, NHS trusts, health authorities, regions and national organisations within the NHS Executive and research organisations.

6.4. The researchers found examples of consumers:

- suggesting topics for research
- commissioning, funding and reviewing proposals
- managing and designing research
- collecting data
- acting as pro-active participants in research, and having some control over the processes of supplying information
- analysing and interpreting results
- reviewing a study or body of work
- disseminating results of research
- implementing findings of research

- reviewing examples of consumer involvement in research
- looking at ethical issues associated with research
- monitoring or auditing existing health services
- setting priorities for health services through needs assessment and other activities
- fund-raising for research
- recruiting participants for research projects.

6.5. The most common of these were i) the involvement of consumers as pro-active participants in research, ii) consumer involvement in monitoring and auditing existing services, and iii) in suggesting or selecting topics for research.

2. A database of health research projects in which black and minority ethnic consumers have been involved

6.6. The Group and the Central Research & 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 Group therefore commissioned Mark Johnson and colleagues at the Centre for Research in Ethnic Relations at Warwick University to compile a database of health research projects in which black and minority ethnic consumers have been involved. This database complements the database developed by researchers at York University, which is described above.

6.7. The Warwick team identified over 200 examples of black and minority ethnic consumer involvement in health research (9). These projects were mainly undertaken by black and minority ethnic community groups and specialist workers. The role of the Department of Health and the NHS Executive in funding initiatives on ethnic health issues has had a significant positive impact on the amount of research undertaken in this area.

6.8. Researchers found a wide variety of examples of people from black and ethnic minority

communities being involved in research. These ranged from examples of consultation about research and dissemination of research findings, and the presence of community representatives on steering groups, through to examples where community groups had proposed, sponsored and managed complete research projects. However, the researchers note that most research in which black and minority ethnic people are involved has been short term and funded by specific project money, and that some health authorities, trusts and voluntary organisations have done very little to ensure that black and minority ethnic communities are involved in initiatives to involve consumers.

6.9. The researchers argue that the involvement of black and minority ethnic consumers in health research has significant benefits for researchers and research funders:

- a greater awareness of the extent of diversity in the population and its implications for practice
- better access to specific groups and communities
- the ability to overcome barriers such as those of language and comprehension
- a wider awareness of the other factors (such as education and housing) that affect people's health and health behaviours
- an improvement in the "equal opportunity" profile of research sponsors or practitioners, potentially opening up new areas or populations to their services
- greater insight into the relevance and effects of ethnically specific cultural issues
- greater ability to ensure that the findings of research can be suitably presented to target audiences

3. A review of the similarities and differences between consumer and professional priorities for health research

6.10. Although some researchers believe that consumer input to research priority setting and research design results in better research, others believe that health care professionals and researchers can act as effective surrogates for consumers. Some research studies show a mismatch between consumer and professional pri-

orities for research, but until recently a review of the nature of these mismatches and their implications had not been undertaken. A research team at Policy, Research, Engineering Science and Technology (PREST) - which is an institute of Manchester University - was commissioned to undertake a review of this area.

6.11. Their study, based on a literature review, survey and interviews, set out to examine what was known about mismatches in health research priorities between professionals and consumers (10). The research team confirmed that mismatches do exist. Indeed, they are likely to be very common and occasionally quite dramatic in scale, especially when there is little dialogue between the various groups.

6.12. For example, at a Royal College of Nursing workshop for consumers and nurses, consumers identified priorities as research on i) long term health needs, ii) the impact of disability on the quality of life for individuals and their families, and iii) the provision of information. Professionals, on the other hand, identified priorities in areas that promoted professional interests - and researchers identified priorities in areas that developed new frontiers of knowledge.

6.13. The study found that a certain level of consensus could often be reached as a result of dialogue, which implies that communication and sharing of information and values can lead to a re-shaping of priorities. In a consultation exercise about priorities for physiotherapy research, for example, physiotherapists raised issues about professional and educational needs, while consumers raised issues about post natal exercises. However, once these two groups had the opportunity to share priorities, mismatches were reduced.

6.14. The team identified that mismatches appear to derive from three distinct sources:

- difference in values and life experiences
- differences in understandings of science and technology and the research process
- differences in access to decision making structures.

6.15. The researchers note that mismatches are also apparent between different groups of professionals - nurses and midwives may indicate

research priorities that are distinctive from those of the medical profession - as well as between groups of consumers.

6.16. They conclude that the weight of evidence and argument supports the view that health research priority setting can benefit considerably - on grounds of equity, efficiency and engagement - from increased consumer participation. They argue that the purpose of this participation should be to allow mismatches to be addressed and to enrich the priority setting process.

Issues arising from these research projects

6.17. These projects demonstrate the value of consumer involvement in health research. In particular, they highlight that:

- Consumers can and do collaborate effectively with researchers at all stages of the research process.
- Most research which has involved black and minority ethnic consumers has been undertaken by community groups and researchers from these communities. It has often been short term.
- To date, little effort has been made by some researchers and research funders - both within and outside the NHS - to involve black and minority ethnic consumers in their work.
- There are mismatches between consumer and professional priorities for research, but a level of consensus can be reached through dialogue. This in turn highlights the importance of communication between consumers and those commissioning research at the prioritisation stage.

6.18. These research projects have also raised questions about the nature of consumer involvement in research. There is no accepted definition about what such involvement is, nor how it should be classified.

6.19. It is clear that any classification will need to address which consumers are involved in the research process, at what stage they are involved, as well as the nature of their involvement. Some work has already been undertaken in this area by Vikki Entwistle and colleagues (11). The Group will be working with the research teams at York and Warwick to further develop a classification system to define the dif-

ferent ways in which consumers can be involved in research (see paragraph 7.5 on page 15).

6.20. The Group is also exploring ways to make the research projects available to others who would find them useful. This might involve the creation of a website or the sale of a computer disk providing information about the projects identified in the databases researched by the York and Warwick teams. A series of seminars is planned, at which the research projects will be disseminated.

example 'd'

THE COCHRANE COLLABORATION

The Cochrane Collaboration is an international organisation that aims to help people make well-informed decisions about health care by preparing, maintaining and promoting the accessibility of systematic reviews of the effects of healthcare interventions. The NHS R&D Levy has been a major source of support for the Collaboration's work.

Cochrane systematic reviews are prepared and maintained by the members of about 50 review groups. They cover most areas of health care from pregnancy and childbirth to stroke and schizophrenia.

In addition, a Consumers and Communication Review Group is preparing reviews of the effects of interventions to improve information and communication among consumers and health professionals.

Consumers have made a significant contribution to all aspects of the Collaboration's work. They have identified and defined topics for systematic reviews, developed protocols and commented on their clarity, searched journals to identify reports for inclusion in the Cochrane Controlled Trials Register, prepared and maintained systematic reviews on their own or in partnership with others, written easy-to-read abstracts of reviews, and added a perspective to the Collaboration's work which would otherwise be missing.

A recent survey in the Collaboration generated many comments by health care professionals

on the benefits of consumer involvement, including:

- they offer a “reality check”
- they bring “an antidote to jargon and pomposity”
- they help make reviews relevant to and readable for everyone, not just health care professionals
- they assist the dissemination of results to the public

But all is not plain sailing. Cochrane review groups need help to develop their capacity to involve consumers. Many consumers need help to find their “niche”, and to gain access to communication and information resources which professionals may take for granted. Improved systems are needed to harness and use consumer involvement effectively. Hard pressed researchers may drop consumer involvement to the bottom of the priority list, unless such involvement is incorporated into the fabric of the review exercise, and appropriately resourced.

Nevertheless, there has been clear progress over the past year in consumer involvement and increasing awareness about its benefits. The Cochrane Collaboration as a whole is taking this message on board, and working towards improved performance.

example ‘e’

EVALUATING DISEASE EDUCATION FOR CHILDREN WITH CHRONIC ARTHRITIS

A project has been developed in Birmingham to develop and analyse disease education programmes for children with chronic arthritis.

A reference group of children and their parents or carers has been established to provide advice and guidance, particularly with regard to the computer-based disease education programme being developed through the project.

In addition, regular meetings are held with children, carers and health care professionals

to assist in the design of a Child Arthritis Self-Efficacy Scale.

This project has been funded by the NHS National R&D Programme on Physical & Complex Disabilities.

example ‘f’

FOLK.US

FOLK.US (pronounced like *focus*) is a collaboration of consumers, researchers and people working in the NHS and Social Services. Based in and around Exeter, the group aims to:

- raise awareness in the research community about consumers’ values, views and knowledge, in order to make research more relevant to people’s lives
- learn from others’ experience about productive methods of collaboration between consumers and researchers
- network with like-minded people
- provide a basis for the development of collaborative projects
- engage with consumers in a way which is productive and useful to them.

FOLK.US will be holding a conference on consumer involvement in health research in March 1999. This is being supported by the South & West Regional R&D Programme and by Devon County Council Social Services Department.

7. Consumers in research in the NHS: The next steps

7.1. This year the Group identified four strategic objectives which will fulfil our terms of reference. These are:

One: to classify the different types of consumer involvement in health research and to promote awareness of this classification system

Two: to develop alliances in order to promote greater consumer involvement in health research

Three: to empower consumers to become more involved in research & development in the NHS

Four: to monitor and evaluate the effects of consumer involvement in NHS research & development.

7.2. The first three of these objectives will enable the Group to make recommendations to the Central Research & Development Committee (CRDC) about how consumer involvement could be enhanced all stages of the research process. The final strategic objective will enable the Group to monitor arrangements in the wider work of the CRDC and its sub-committees.

7.3. These objectives also seek to ensure relevance to the Government's white paper, *A New NHS, Modern, Dependable* and the green paper on public health, *Our Healthier Nation*.

7.4. The Group has developed a work plan based on these objectives. This was approved by the CRDC in July 1998, and work has begun to put it into action. progress will be reviewed against the plan on a regular basis, and reported to the CRDC accordingly.

An outline of our strategic plan for 1998-2000 is described in more detail as follows:

Strategic Objective One: To classify the different types of consumer involvement in health research and to promote awareness of this classification system.

Background

7.5. We recognise that a wide range of people come within our broad definition of "consumer", and that consumers may be involved in R&D in different ways and at different stages of the research process. They may become involved through various mechanisms at any point from the initial identification of possible research topics, through the prioritisation, commissioning, and undertaking of research, to the dissemination of results. In order to monitor and evaluate consumer involvement in research and development, it is necessary to describe such involvement in a standardised way.

7.6. Researchers compiling the databases outlined in Section 6 of this report have developed an initial framework to describe consumer involvement in research, and at what stages in the research process they have been involved. The Group now aims to produce a more detailed classification system through which to describe consumer involvement in health research. It is hoped that this will be adopted for use by consumers, people working with and in the NHS, and those who commission and undertake research.

Proposed work on Objective One to March 2000

7.7. To support the researchers who are compiling the databases described in Section 6 to organise a seminar for agencies and organisations that are actively involving consumers in health research. Participants will discuss the initial classification system for consumer involvement in health research, and draw up proposals about how this might be developed. This seminar will be written up and disseminated to interested researchers and consumers.

7.8. To organise a seminar for consumers who are involved in health research, so that they can develop their thinking about an appropriate classification system to describe their involvement. Again, this seminar will be written up and disseminated to interested researchers and consumers.

7.9. To write up a classification system based on

the seminars described above and to ensure that this is widely disseminated to consumers, researchers and those working in the NHS.

7.10. To include discussions about this classification system within a second major conference to be organised by the Group, which is planned for January 2000.

Strategic Objective Two: To develop strategic alliances with key groups in order to promote greater consumer involvement in health research.

Background

7.11. Although there is significant interest and enthusiasm amongst consumers and NHS staff for the whole subject of consumer involvement, there is also some confusion about the various strategies and programmes in place. There is considerable scope for awareness-raising and clarification. Forging good alliances with relevant groups is one way to facilitate this.

7.12 In addition, consumers and those working within the NHS express some frustration about the apparent gap between research, strategy and practice. The Group recognises the need to address the factors that inhibit getting research into practice, as consumers have stated that this is a priority for them. Again, developing strategic alliances with key groups is a way forward. The Group aims to help to link research and practice in the NHS and to show how consumer involvement at every stage of the cycle can improve quality, in order to promote increased consumer involvement in research and development in the NHS.

Proposed work on Objective Two to March 2000

7.13. To strengthen links with a number of key groups, in particular:

- patient organisations
- those working on other parts of the Patient Partnership Strategy
- those involved in national R&D programmes
- regional R&D offices
- the National Institute for Clinical Excellence
- the Medical Research Council

7.14. To do this, a seminar was held in January 1999 to share experience and to develop an action plan which will provide clarity, promote the involvement of consumers at all stages of the research process, and help close the gap between research, strategy and practice.

7.15. To build links with those responsible for developing the Department of Health's new research strategy, "Research for Health and Social Care." This is to ensure that consumers are involved in this process, and that the strategy makes a clear commitment not only to the involvement of consumers in research and development in the NHS, but also to transparency of decision making.

Strategic Objective Three: To empower consumers to become more involved in research and development in the NHS.

Background

7.16. Some consumers need additional support, knowledge or skills to enable them to become more actively involved in the research and development process. Some consumers are traditionally excluded from the research process: people with physical or learning disabilities, non-English speaking people and those from minority ethnic communities, for example. The Group wishes to ensure that people from these groups have opportunities to become more involved in health research, in order to ensure that the outcomes of such research is relevant to a wide range of the population. We also recognise that health professionals may need additional skills to enable them to effectively involve consumers in health research.

Proposed work on Objective Three to March 2000

7.17. To publish and disseminate the Consumer's Guide to R&D in the NHS, particularly targeting voluntary organisations, community health councils and other organisations committed to involving consumers, including those representing minority groups.

7.18. To develop a set of briefing notes outlining learning to date, to be used by consumers wishing to be involved in health research, and by researchers who wish to involve consumers in health research.

7.19. To commission an action research project with the aim of:

- establishing some generalisable guidelines about ways to involve consumers in research and development at a local level
- identifying consumer priorities for training.

The project will work with a variety of trusts, health authorities and primary care groups committed to involving consumers, and with consumers who wish to become involved in research in the NHS.

7.20. To investigate the ways in which consumers have been empowered to become involved in research and development in other fields - in social services and public health, for example.

7.21. To develop and support a network of people and groups committed to consumer involvement in health research. This will include the development of a database of contacts, a newsletter and a website.

Strategic Objective Four: To monitor and evaluate the effects of consumer involvement in NHS research & development.

Background

7.22. The Group's terms of reference require it to monitor arrangements for consumer involvement in the wider work of the Central Research and Development Committee and its sub-committees. It is important to assess the impact of consumers' involvement in the research and development process. To do this, the Group must first be able to describe what is meant by "consumer involvement in health research" (see objective one).

Proposed work on Objective Four to March 2000

7.23. To ensure that the NHS Executive's study of annual reports made by Budget One recipients includes information about how these recipients have involved consumers. (Budget One is used to help the providers of NHS services, for example NHS trusts, to undertake research.)

7.24. To follow up a sample of these responses in more detail in order to develop a set of case

studies about the involvement of consumers in R&D within Budget One - and to disseminate these case studies.

7.25. To continue to be actively involved in the Health Technology Assessment Programme project to involve consumers, to press for ongoing evaluation of the impact of this involvement, and to follow up any initiative to continue this work.

7.26. To monitor consumer involvement in the new Service Delivery and Organisation national programme and to press for ongoing evaluation of the impact of this involvement.

7.27. To monitor and evaluate consumer involvement in regional NHS R&D programmes.

7.28. To monitor how the UK Cochrane Centre, the Centre for Reviews and Dissemination and the Cochrane Collaborative Review Groups receiving infrastructure funding through the NHS R&D Levy are involving consumers in their work, and to evaluate the impact of this involvement.

7.29. To identify research units that actively involve consumers in selecting topics for and/or designing clinical trials; to develop agreed guidelines for good practice in such involvement; and to monitor the work of these groups to involve consumers.

Membership of the Standing Group on Consumers in NHS Research

7.30. During the past year the Group has worked with the Director of R&D in the NHS to review membership and to agree a term of office. Some members of the Group have resigned, due to other commitments. This year, the Group will be recruiting new members to assist us in achieving our objectives.

7.31. The Group's long term goal is to ensure that consumers are involved as a matter of course in research and development in the NHS at national, regional and local levels.

8. Where to go for more information

For more information about the Group and our work, please contact:

Bec Hanley
Consumers in NHS Research Support Unit
Help for Health Trust
Highcroft
Romsey Road
Winchester SO22 5DH

Phone: 01962 849100
Fax: 01962 849079
e-mail: conres@hfht.demon.co.uk

example 'g'

THE DISCERN PROJECT

The Anglia and Oxford Region have funded a project to develop a questionnaire which will enable patients and information providers to judge the quality of written information about treatment choices. Called DISCERN, the questionnaire will also facilitate the production of new, high quality evidence-based health information for consumers.

An expert panel generated criteria by which health information could be judged. Three of the panel members were consumers with direct experience of the medical conditions being considered.

The resulting questionnaire was tested by a national sample of 15 information providers and 13 self-help group members, using a random sample of leaflets. DISCERN was found to be a reliable and valid instrument - which can be used both by information providers and by patients - to judge the quality of written information about treatment choices.

example 'h'

THE NATIONAL PRIMARY CARE RESEARCH AND DEVELOPMENT CENTRE

With the assistance of a grant from the King's Fund, staff at the National Primary Care Research and Development Centre (NPCRDC) have developed a guidebook of evidence-based medicine for people with ulcerative colitis. It is designed to empower patients and allow them to participate in making informed choices about their medical and surgical care. Patients and self-help groups were active partners in the development of the guidebook - they were involved in the recruitment of the researcher, the selection and co-ordination of other consumers, the discussion of issues in focus groups, and individual assessment of the guidebook.

The North West Regional R&D and the Health Technology Assessment Programmes are now funding evaluations of the guidebook, which will be published in May.

Hope Hospital in Salford and the NPCRDC are now developing a guidebook on irritable bowel syndrome, again involving consumers.

APPENDIX ONE

The Standing Group on Consumers in NHS Research

Terms of Reference

Our terms of reference are:

a) To review ways in which consumer views have been addressed in all stages of the NHS R&D Programme to the end of December 1996.

b) 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 R&D process. This would include:

- advising on priorities to be addressed in new research within the NHS R&D 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.

c) To monitor arrangements for consumer involvement in the wider work of the CRDC and its sub-committees.

d) To advise on priorities for a programme of commissioned research into consumers' involvement in the NHS R&D Programme.

e) To report regularly to the CRDC.

APPENDIX

TWO

The Standing Group on Consumers in NHS Research

Membership

Chair: Ruth Evans
Director, National Consumer Council

Vice chair: Iain Chalmers
Director, UK Cochrane Centre (to December 1998)

Harry Cayton - Director, Alzheimer's Disease Society (Chair of Strategic Alliances Sub-Group, Vice chair from January 1999)

Annie Bartlett - Senior Lecturer in Forensic Psychiatry, St George's Hospital Medical School (to December 1998)

Carol Baxter - School of Nursing & Midwifery, University of Manchester

Jane Bradburn - Lynda Jackson MacMillan Centre for Cancer Support and Information, Mount Vernon Hospital (Chair of Empowerment Sub-Group)

Peter Cardy - Chief Executive, Multiple Sclerosis Society (from June 1998)

Liz Clough - Associate Director of R&D, NHS Executive Trent Regional Office (from October 1998)

Chris Davies - Director of Social Services, Somerset County Council (to July 1998)

Vikki Entwistle - Senior Research Fellow, Health Services Research Unit, University of Aberdeen Medical School

Christina Funnell - European Editor, The Patients' Network (to December 1998)

Bob Gann - Director, Help for Health Trust

Diana Garnham - General Secretary, Association of Medical Research Charities

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

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

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

Julie Jones - Director, Westminster Social Services (from December 1998)

Alistair Kent - Director, Genetic Interest Group

Barbara Meredith - Senior Policy and Development Officer, National Consumer Council and Chair, Patients' Forum (to December 1998)

Nick Partridge - Chief Executive, Terence Higgins Trust (Chair, Monitoring & Evaluation Sub-Group)

Maggie Pearson - Regional Director of Research and Development, NHS Executive North West Regional Office and Director, Service Delivery and Organisation Programme

Caroline Woodroffe - Freelance Health Service Researcher

Observers:

Val Billingham - Patient Partnership Strategy Co-ordinator, NHS Executive

Joan Box - Medical Research Council (from October 1998)

Fiona Russell - Medical Research Council (to October 1998)

Secretariat:

Bec Hanley - Director, Consumers in NHS Research Support Unit

Morton Phillips - Research & Development Division, NHS Executive

Jackie Thorpe - Research & Development Division, NHS Executive (to August 1998)

Rod Toohar - Research & Development Division, NHS Executive

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