

Working partnerships

Consumers in NHS Research
3rd Annual Report

Author: Bec Hanley, on behalf of
Consumers in NHS Research

Further copies from: *Consumers in NHS Research
Support Unit,*
Help for Health Trust,
Highcroft, Romsey Road,
Winchester SO22 5DH

Date of issue: October 2000

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 and potential patients
- carers
- long term users of services
- organisations representing consumers' interests
- members of the public who are the potential recipients of health promotion programmes
- 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 acceptable term used by these groups to describe themselves. We also recognise that there are many different definitions of the term “consumer.”

We are all potential consumers of health and social services. However, consumers who get involved in R&D and do not have other “professional” roles (such as doctor, researcher etc) have a distinct and complementary role to play in the R&D process.

By “consumer involvement” in R&D we mean an active partnership between consumers and researchers in the research process, rather than the use of consumers as the “subjects” of research.

Many people describe consumer involvement in R&D as doing research *with* consumers rather than to, about or for consumers.

Contents

• A note about the language used in this report	1
• Foreword by Professor Sir John Pattison	3
• Executive summary	4
1. Introduction	5
• <i>Consumers in NHS Research</i>	
• <i>The Consumers in NHS Research Support Unit</i>	
• Examples and quotes	
2. Our work during 1999/2000	
• Strategic Objective One: Developing Alliances	7
• Research: Who's Learning?	
• Research and Development for a First Class Service	
• Strategic Objective Two: Empowering Consumers	8
• Publications	
• Training	
• New research	
• Strategic Objective Three: Monitoring and Evaluation	9
• Research undertaken in 1999/2000	
• Other activities in 1999/2000	
• Consumer involvement within R&D in the NHS Service Delivery and Organisation, Health Technology Assessment, New and Emerging Applications of Technologies, Forensic Mental Health	11
• Consumer involvement in health R&D beyond the NHS Medical Research Council, UK Co-ordinating Committee for Cancer Research, the Alzheimer's Society, the Toronto Group	13
3. Our plans for 2000/2001	15
• Strategic Objective One: Developing Alliances	
• Strategic Objective Two: Empowering Consumers	
• Strategic Objective Three: Monitoring and Evaluation	
4. How to contact us	17
• Appendix One: Terms of Reference	18
• Appendix Two: Membership	19

Throughout this report, you'll find examples of consumer involvement in research funded by the NHS.

We have also included a selection of quotes from people who are actively working towards consumer involvement in R&D in the NHS.

Foreword

In 1991, the first director of R&D for the NHS gave a commitment to involve consumers in the research and development that we support. Nearly ten years on, impressive developments have taken place. There is still much work to do but this report, the third by *Consumers in NHS Research*, illustrates the progress that has been made.

This progress is due in no small part to the productive work of those involved in *Consumers in NHS Research*. In the financial year 1999/2000, this group has organised a major national conference, produced a number of very useful publications and undertaken research on how consumers are currently involved in health research. Most important, members of *Consumers in NHS Research* have worked to ensure that the involvement of consumers in NHS R&D becomes a mainstream activity.

I and my colleagues recognise that there are still important questions to answer about the involvement of consumers in NHS R&D. For example, no systematic evaluation has been undertaken to assess the impact of the involvement of consumers in the research process. We do not yet know at what stages in the research process it is most effective and appropriate to involve consumers.

I look forward to working with *Consumers in NHS Research* to address these and other questions in the coming years.

A handwritten signature in black ink that reads "John Pattison". The signature is written in a cursive style with a large, prominent initial 'J'.

John Pattison
Director of Research and Development
Department of Health

Executive summary

Consumers in NHS Research, a sub group of the NHS Central Research and Development Committee, was set up in 1996. It aims to ensure that consumer involvement in NHS R&D improves the quality of research. In 1999 a Support Unit for the Group was established at The Help for Health Trust in Winchester.

This is the third report of *Consumers in NHS Research*. It outlines work undertaken during the financial year 1999/2000, and plans for the year 2000/2001. The report also includes examples of research initiatives which have actively involved consumers, and quotes from those who are actively committed to consumer involvement in health research.

In the past year, *Consumers in NHS Research* has:

- held a major national conference, entitled Research: Who's learning?
- published a guide to NHS R&D for consumers
- published a set of briefing notes for researchers on how to involve consumers
- commissioned new research on consumer involvement in research in other, related fields
- undertaken research on consumer involvement in randomised controlled trials and on how consumers are involved in NHS Executive regional R&D offices
- supported the development of consumer involvement in national NHS R&D programmes and in initiatives to involve consumers in health research beyond the NHS

During the financial year 2000/2001, *Consumers in NHS Research* will continue to focus on work to achieve its three strategic objectives. These are:

- To develop strategic alliances with key groups in order to promote greater consumer involvement in health research
- To empower consumers to become more involved in NHS R&D
- To monitor and evaluate the effects of consumer involvement in NHS R&D

1. Introduction

The NHS has been running a programme of research and development (R&D) since 1991. This year (2000) a new strategic framework for NHS R&D funding was launched - *Research and Development for a First Class Service: R&D funding in the new NHS*¹. This document sets out how NHS R&D funding will be managed in the future, and endorses the principle of partnership to ensure the best possible R&D to benefit people who use the NHS.

Research and Development for a First Class Service reinforces a policy commitment to involving consumers in the work it undertakes - not as the "subjects" of research, but as active participants in the research and development process.

Consumers in NHS Research

In 1996 the Central Research and Development Committee, which advises the Director of R&D in the NHS about the direction and focus of R&D, set up a unique sub-group to advise them on how best to involve consumers in the R&D process. This sub-group is called *Consumers in NHS Research*².

Consumers in NHS Research aims to ensure that consumer involvement in R&D in the NHS improves the way that research is prioritised, commissioned, undertaken and disseminated. We believe that the involvement of consumers in the research process leads to research that is more relevant and more likely to be used. If research reflects the needs and views of consumers, it is more likely to produce results that can be used to improve practice.

In 1999 the Central Research and Development Committee approved new terms of reference for *Consumers in NHS Research*. These are included in this report in Appendix One.

Consumers in NHS Research is chaired by Nick Partridge, Chief Executive of the Terrence Higgins Trust. Our vice chair is Harry Cayton, Chief Executive of the Alzheimer's Society. The Director of R&D for the NHS appoints our members.

They come from voluntary organisations, research, health and social services management. A list of our members is included in Appendix Two of this report.

The Consumers in NHS Research Support Unit

In February 1999 we established a Support Unit. Based at the Help for Health Trust in Winchester, the Unit provides an institutional base for the Group. It offers information, advice and support about consumer involvement in NHS R&D to consumers, researchers and those working in the NHS.

We have three (mainly part time) staff working at the Unit. They are:

- Bec Hanley, director
- Sarah Buckland, research co-ordinator
- Barbara Dawkins, administrator

Sarah Gorin, our action researcher, left in September 2000. In January 2000 we appointed a northern development manager, Sue Straughair. She has joined us for a year on a part time secondment from the Northern and Yorkshire Region of the NHS Executive.

Examples and quotes

The involvement of consumers in health research has increased substantially since our last report, *Involvement Works*. To illustrate the range and extent of this involvement, we have included a number of examples throughout this report. Many of them are drawn from workshops given at our conference in January 2000 (see page 7).

We have also included some quotes from people who are actively committed to the collaboration of consumers, researchers and research funders in the research process. These quotes have been drawn from a video made for our conference (see page 7).

We hope that they will help to illustrate the exciting possibilities involved in such collaborations.

¹Department of Health (2000) *Research and Development for a First Class Service: R&D funding in the new NHS*

²*Consumers in NHS Research* was previously known as the *Standing Advisory Group on Consumer Involvement in the NHS R&D Programme*

example 'a'

RESEARCH UNDERTAKEN BY VISUALLY IMPAIRED PEOPLE

A research project called *Losing sight in Ryedale*³ was undertaken by a Group for people with serious sight loss living in Ryedale. The project was sponsored North Yorkshire Health Authority and North Yorkshire Social services Department. The authors examined the systems designed to identify and assist those losing sight, particularly the national system of registration as a blind or partially sighted person. This system involves both health and social services, but service users are in the unique position of experiencing the system from beginning to end. The Group also commissioned a professional researcher to interview 28 visually impaired people about their views and experiences.

The study considered how successfully the system meets the needs of visually impaired people. It focused on people living in the community, aged 55 and over, with sight problems. The central finding was that weak links between the different parts reduced the system's effectiveness. The study suggested the creation of a structure to foster exchange of views and discussion of problems between NHS service providers, social services, voluntary organisations and service users. It also made a number of detailed recommendations. These included:

- The implementation of simple procedure for referring people with temporary sight loss to social services
- The expansion of the role of the optometrist
- A referral system for community optometrists to benefit people with untreatable eye conditions
- A revised system to remove current anomalies in the system for supply of low vision aids
- A monitoring system to identify later needs for further rehabilitation caused by continuing sight loss
- Increased training in mobility and daily living skills
- The study also noted the absence of new technology from the main rehabilitation agenda. The authors have therefore

recommended to the Department of Health that they work with others to develop a strategy to restore literacy and increase independence of visually impaired people through the medium of access technology

- Improved training of non-specialist social services staff to ensure adequate awareness of the effects of visual impairment

In response to this research, the local health authority has agreed to include a new intention in the Health Improvement Plan for the next year - the intention to establish a Low Vision Services Development Group to identify a low vision service framework. This Group includes service users and carers as well as people from the voluntary sector, NHS, social services and the health authority. The Social Services Department has engaged a part time member of staff with a remit to help the Rehabilitation Officer establish an experimental system of long term monitoring of need.

³Crookes J, Popham R, Thirlway M (1999) *Losing Sight in Ryedale* Malton and Norton In Touch

"It's very important that people with disabilities are involved in research projects.... their experiences can more often than not make the outcomes of the research more relevant, more accurate and more applicable. We wouldn't contemplate doing any research project that didn't involve disabled people." (Consumer)

"Being a user researcher gives me a clear sense of purpose. For me there's no point in research unless it can lead to something happening which makes things better for people. If you're linked with organisations and groups then it's not just you as a researcher writing some clever thing and then you put it somewhere and people are meant to take notice of it... you know there are people working alongside you who are interested in doing something with it." (User Researcher)

2. Our work during 1999/2000

In 1998 we developed a Strategic Plan to help us to take forward our aims and to meet the terms of reference that were given to us by the Central Research and Development Committee of the NHS. This Plan, updated in 1999, has three key strategic objectives. These are:

- To develop alliances with key groups in order to promote greater consumer involvement in health research
- To empower consumers to become more involved in R&D in the NHS
- To monitor and evaluate the effects of consumer involvement in NHS R&D

Below, we describe the work we have undertaken during the past year (1999/2000) to help us to meet these objectives.

Strategic Objective One: Developing Alliances

Research: Who's Learning?

Within our first strategic objective, our key task for 1999/2000 was to organise a national conference. This took place in January this year. Entitled *Research: Who's Learning?*, the conference aimed to promote consumer involvement in health research, build alliances and share learning amongst consumers, researchers and those working in the NHS.

The conference was hugely oversubscribed, with 300 people attending and a further 70 people turned away due to lack of space. The programme aimed to promote as much involvement by participants as possible, and therefore included workshops, posters, a soapbox, a discussion and an interactive theatre presentation as well as a keynote speech by Lord Hunt of Kings Heath, Parliamentary Under Secretary of State for Health.

Workshops focused on consumer involvement in research in mental health, maternity care, children and families, learning disabilities and many other

areas. There were also workshops on a range of techniques or themes, such as user led research, consumer involvement in prioritising research topics and how consumers are involved in national NHS R&D programmes.

Feedback from the conference was extremely positive, with 95% of participants stating that they had enjoyed the conference, and 70% saying they learned a great deal or quite a lot about consumer involvement in health research.

In order to encourage contributions from consumers who were not able to come to the conference, we asked them to tell us on video about what research meant to them and why they thought it was important to be involved. This project developed to include contributions from researchers about their views on consumer involvement in health research. We now plan to use this video as a training tool. (Quotes from contributors are included throughout this report).

A conference report has been published.

Research and Development for a First Class Service

March saw the launch of the new NHS R&D strategic framework - *Research and Development for a First Class Service*. We were pleased to have an input to this new document, and we welcome the commitment it makes to consumer involvement across the NHS R&D Programme.

"I've spent all my working life involved in research. The great change for me has been involving consumers. Naively, I thought 'but I've always involved consumers' but then I gradually realised we should ask the consumer what research they want and how they might measure it and what it would mean to them, and the purpose from their point of view... which is a bit like standing on one's head. So I think this is a very interesting switch from my point of view - from not just using people in research but really making the user the person in charge. What one's really got to do is to give one's skills to the user. Which is great." (Researcher)

Strategic Objective Two: Empowering Consumers

We recognise that it is important to develop the capacity of consumers to become involved in R&D in the NHS and beyond. Whilst some consumers feel able to deal with the complex structures of NHS R&D, others welcome training and support to help them to take a full part in health research. One of our key tasks this year has been to produce information for consumers to ensure they have the tools to understand R&D in the NHS.

Publications

In June 1999 we published *Research and Development in the NHS: How can you get involved?* Consumers and those working in the NHS are using this guide to begin to understand the complexities of R&D in the NHS. The guide makes suggestions about how consumers can get involved in R&D, and gives useful contacts and practical advice. This has been a very popular publication, for which we continue to have many requests. With the publication of a new R&D strategic framework, this guide will need to be updated. We are currently exploring the most appropriate way to do this.

Whilst there is a need to build capacity amongst consumers, there is also a need to help researchers to involve consumers effectively. In January this year we launched *Involving Consumers in Research & Development in the NHS: Briefing Notes for Researchers*. Since *Consumers in NHS Research* was established in 1996, we have received a number of requests from researchers and research commissioners for practical advice on how best to involve consumers. These briefing notes were developed by a group of consumers and researchers in response to these requests. The publication has been very well received, with many researchers asking for further copies to distribute to their colleagues.

Training

Another way in which the capacity of consumers to become more actively involved in R&D in the NHS can be developed is through training. In December 1999 we brought together key agencies that are offering training in this area. They asked

us to ensure that the training they offer is publicised. We have done this by providing information at our conference and on our website. During the next financial year, we will be exploring this issue further (see page 15).

New research

Consumers in NHS Research recognises that we have much to learn from the involvement of consumers in research in other, related fields - for example in social care, the environment, and health promotion. We have therefore commissioned a study to examine the ways in which consumers have been empowered to become involved in R&D in other fields, and to make recommendations about how this learning can inform our work within the NHS. The project will also receive some funding from the Centre for Evidence Based Social Services (located in Devon).

Work will commence on this project in September 2000 (see page 15) and will be based at Exeter University.

The steering group for the project includes consumers from Folk.us (a collaboration of consumers and researchers based in Exeter), researchers from different fields, a health professional and representatives from the commissioning bodies.

"I think patients have much to teach not just for the NHS but the pharmaceutical industry. We do a lot of R&D and I think we could focus our R&D more effectively by working at an earlier stage with patients." (Researcher)

"I had two not very pleasant birth experiences and ended up co-ordinating the Maternity Users' Group. It's a chance to contribute to improving services with other women. We have a good relationship with the professionals... the researchers listen to what we've got to say and if we've any particular views they take them into consideration. It all hinges on what sort of relationship you can form with the research department and they have to be willing to involve the users and not be threatened. Professionals have to realise that the users aren't there to threaten their jobs." (Consumer)

Strategic Objective Three: Monitoring and evaluating the effects of consumer involvement in NHS R&D

Research undertaken in 1999/2000

We have undertaken two pieces of research during the past year, both under the auspices of the Monitoring and Evaluation Sub-Group. These are:

- A survey of the nature and extent of consumer involvement in randomised controlled trials in the UK
- A study of consumer involvement in the regional NHS R&D programmes and R&D Support Funding for NHS Providers

The involvement of consumers in randomised controlled trials (RCTs)

RCTs are seen by many as providing the gold standard in health research and the underlying basis for evidence based health care. Despite the interest in consumer involvement in RCTs from some consumers and researchers, there is very little policy guidance that advocates such involvement. It is also often not easy to trace, from reading reports in journals, whether trials have actively involved consumers, as this involvement is rarely mentioned. Hence researchers who wish to initiate active participation by consumers find it difficult to learn from the experience of others.

In response to this, in 1998 we commissioned a study to assess the nature and extent of consumer involvement in RCTs in the UK. This study, which was completed in early 1999, was undertaken by staff at the *Consumers in NHS Research Support Unit* in partnership with colleagues at the London School of Hygiene and Tropical Medicine.

The study focused on specialist trials centres that manage most of the large non-pharmaceutical RCTs in the UK. It was based on a database that was used to establish a National Register of Clinical Trials Offices and Clinical Trials Support Units in 1997. A questionnaire was sent to a named person at each UK centre asking about the involvement of consumers in the overall work of the centre (eg: identifying topics for trials)

as well as about the involvement of consumers in RCTs co-ordinated by the centre and future plans. The survey found that 34% of trials co-ordinating centres that responded to the questionnaire already involved consumers in at least some aspect of the RCT research process and a further 29% said they planned to involve consumers in the future.

19 of the 62 centres identified trials which had actively involved consumers. Of these 19 centres, 10 reported only one such trial and one centre reported 14 trials, with a remaining 8 centres reporting between 2 and 7 trials.

Based on these responses, a second questionnaire was sent to contacts for the 60 individual trials identified. 48 respondents were considered eligible for this part of the survey.

Most of the trials identified in the survey which involved consumers took place in the perinatal, HIV/AIDS and cancer fields. Consumers were most often involved in drafting or reviewing patient information leaflets for the trial, developing the trial protocol, and in promoting recruitment to the trial. The only stage at which consumers were not involved was in data monitoring committees. Patients and potential patients, members of self help groups and members of organisations representing consumers' interests were involved more often than other "types" of consumers.

The survey also asked about the impact of consumer involvement. Respondents told us that consumers helped to ensure that the trial was relevant, that it addressed questions that were answerable and that the trial would work in practice. This included making aspects of the trial user friendly and assisting in recruitment. Consumers were also able to feed back to researchers information "from the ground" about how the trial was being received. Respondents told us about the many constructive relationships developed as a result of consumer involvement.

Overall, the study found relatively few instances of consumer involvement in RCTs. Respondents gave a number of reasons for this lack of involvement. Many said that they had not thought about involving consumers. We hope that dissemination of this survey and the planned workshop (see page 16) will help to raise awareness. There is already evidence of change, as some centres said they planned to involve consumers in future.

Consumer involvement in the regional NHS R&D programmes and R&D Support Funding for NHS Providers

For some time we have been aware of the variation in the nature and extent to which consumers are involved in the work of NHS R&D regional offices and in the NHS Trusts and other organisations that receive NHS R&D Support Funding.

In 1999 we began a study to map this involvement. We hoped that this would enable us to build links with staff at regional offices, and to share experience and information across the regions in order to promote the development of consumer involvement.

During 1999 staff at the *Consumers in NHS Research Support Unit* undertook interviews with key individuals in regional offices, and examined annual reports for 1998/99 which had been presented by NHS organisations to the regional offices.

Interviews with regional staff highlighted that they had different interpretations of the terms “consumer” and “involvement” and that this influenced the way in which regions responded to the policy commitment to involve consumers. Most of those interviewed supported the principle of consumer involvement.

They felt that consumers could:

- ensure that research is more relevant
- provide a different perspective
- address ethical concerns of patients
- encourage the participation of other consumers in R&D

Key concerns centred on whom to involve, the need for research evidence to confirm the value of consumer involvement and the lack of time and resources to involve consumers effectively.

Consumer involvement in activities undertaken through regional R&D offices has included:

- membership of committees responsible for prioritising or commissioning research
- involvement in the research prioritisation process, for example through special workshops, surveys or meetings
- reviewing applications for research funding

We also studied annual reports submitted to regions by NHS organisations in receipt of Support Funding, to begin to ascertain the degree of consumer involvement in this area of NHS R&D.

Documentary information was limited, as not all NHS organisations receiving Support Funding gave detailed information about whether or how they were involving consumers, despite this being required through the system of performance monitoring. However it was possible to ascertain that of the 248 Annual Reports examined, 42% reported that consumers were involved in the R&D activities of the organisations receiving Support Funding, and a further 8% planned to do so in future. However, in 58% of organisations receiving R&D Support Funding, consumers had not been involved in any research activities.

There were two main ways in which these organisations involved consumers. 30 involved consumers in strategic initiatives such as membership of R&D committees, the development of policy about consumer involvement and the development of application forms. 51 involved consumers in individual research projects. In these, the most common way of involving consumers was in planning and designing research. Other examples of involvement included:

- a consumer as a co-applicant for a research project
- using a noticeboard in a GP surgery to consult patients about priorities and topics for research
- consumers acting as interviewers
- consumers presenting the findings of research at a conference

A further 22 organisations involved consumers both at a strategic and individual project level.

We will continue to offer support and advice to regional offices and NHS Trusts and primary care organisations to promote the increased involvement of consumers in R&D at all levels within the NHS.

"We hope that by using people who have experience of using drugs as researchers, they (the research participants) will come out with more honest answers than if the researcher was doing the research on her own." (Consumer)

Other activities in 1999/2000

In addition to carrying out tasks related to our Strategic Plan, we have been pleased to support a number of other initiatives both within and beyond the NHS. These are outlined briefly below, in order to illustrate the range of activity that is now taking place to promote consumer involvement in health research.

Consumer involvement within R&D in the NHS

Service Delivery and Organisation

The Service Delivery and Organisation (SDO) R&D Programme is an NHS national R&D Programme with the remit of producing and promoting the use of research evidence directed at improving the organisation and delivery of health care services.

During autumn 1999, the centre that manages the SDO R&D Programme carried out a national listening exercise. This brought together a wide range of stakeholders in focus groups around the country and in some expert groups, using structured discussions within a common framework.

The purpose of this exercise was to enable the SDO R&D Programme to understand what issues are most important to those delivering and organising services, and to those receiving them, and to secure their ownership of the Programme.

A wide range of people were consulted during this process, including service users, health care professionals, health service managers, researchers and others. The listening exercise highlighted, amongst other issues, that service users should continue to be involved in all aspects of the SDO Programme.

A Commissioning Board to oversee the work and development of the Programme has recently been established. The Board membership comprises service users, health care professionals, health service managers, researchers and policy makers.

We welcome the commitment to consumer involvement that SDO has demonstrated through its involvement of consumers from the outset of the work of this new programme.

Consumers in NHS Research was pleased to advise on and be involved in this listening exercise. We will continue to promote the involvement of consumers in this programme.

example 'b'

INVOLVING PEOPLE FROM BLACK AND MINORITY ETHNIC COMMUNITIES IN RESEARCH

The Health Panel for Minority Ethnic Communities was established to involve the minority ethnic communities in and around Dewsbury in identifying their health needs. This involved Kirklees Council, Kirklees and Calderdale Health Authority, Dewsbury Community Health Council, Dewsbury NHS Trust and residents of Dewsbury.

24 interviewers from the local community were recruited and trained in interview techniques. Community interviewers used door-to-door interviews to recruit residents to the Health Panel. A questionnaire was developed in consultation with the community interviewers, and this was used to interview panel members. After receiving training in focus group methods, community interviewers discussed the findings with community groups and statutory organisations.

The project was able to identify health issues important to the local community in priority order. Priorities differed with age, sex and social class. Through collaboration between the community and statutory organisations, the project also achieved practical results for example a diet and exercise class for local women.

The project was successful in involving minority ethnic communities in identifying priorities related to health issues and implementing solutions. It also demonstrated the value of involving community representatives at an early stage in the research process. One of the key lessons was that collaboration requires real commitment from and appropriate accountability within statutory organisations.

"What I'm concerned about is how we make the academic process one which is actually answerable to the needs and concerns of ordinary folk, rather than being separate and in a world of its own." (Researcher)

Health Technology Assessment

Health technologies are interventions used to help people avoid, recover from or cope with any health problems. They include the use of medicines, healthcare procedures and settings of care. The Health Technology Assessment (HTA) Programme asks questions such as: Does the technology work? For whom? At what cost? It focuses on existing products and services.

The HTA Programme has been actively committed to the involvement of consumers for several years, and has a member of staff with specific responsibility for this work. *Consumers in NHS Research* has been pleased to assist the HTA Programme in this area.

There are now consumers on all of the HTA's advisory panels. These panels identify and prioritise research questions to be addressed. Consumers are also involved in commenting on research proposals, summaries and reports. Staff working for the HTA Programme have also set up a mentoring scheme for consumers, whereby those with more experience of working with the programme, or with more technical expertise, can offer support and advice to consumers new to this process.

New and Emerging Applications of Technologies

The New and Emerging Applications of Technology (NEAT) Programme is a new element of the NHS R&D Strategy. It aims to support research that will lead to the development of new and improved clinical products and procedures.

There are two consumer members of the NEAT committee, nominated by *Consumers in NHS Research*. A number of proposals for research have been reviewed by consumers. Staff working on the NEAT programme have also encouraged those submitting funding proposals to involve consumers in their research. A call issued in June 2000 particularly welcomed proposals in National Priority areas, including cancer, coronary heart disease and mental health.

Forensic Mental Health

We have been pleased to support the development of consumer involvement in the field of forensic mental health. The National Programme on Forensic Mental Health R&D, building on work undertaken by the High Security Psychiatric Services Commissioning Board, has been actively working to involve consumers. Two service

users have been appointed to the Programme's Advisory Committee, and the views of service users have been incorporated when determining the key R&D questions for future commissioning.

example 'c'

INVOLVING CONSUMERS IN AN NHS REGIONAL R&D OFFICE

The South West region of the NHS Executive covers a large region of England, and stretches from Gloucestershire to Land's End. Managers in this region have successfully involved consumers in a number of initiatives.

In 1999 the region introduced a question to its application form for research funding asking researchers if consumers had been involved in the development of the grant application, and whether they would be involved in undertaking or monitoring the research. Although this is not a condition of funding, staff in the region expect that this question will encourage researchers to involve consumers in the development of research questions and protocols.

Some grant application forms are sent to voluntary organisations for review before decisions are made about whether applications should be funded.

In 1999 the South West Region was the first in the NHS Executive to award a research grant to a consumer to undertake a research project. Peter Vance developed a handwriting disorder similar to writer's cramp 16 years ago - he is now undertaking research to identify relevant coping strategies for writer's cramp type disorders. Little is known about this condition, or about its treatment.

In 1999 the South West Region also awarded a grant to Folk.us, a collaboration of consumers, researchers and health professionals. This grant will enable the group to support the development of collaborative research involving consumers, form links with national and regional organisations, promote mutual learning by the development of educational tools and training events, and disseminate the outputs of Folk.us.

Consumer involvement in R&D beyond the NHS

We welcome the development of a number of other significant initiatives to involve consumers in health research, which have taken place outside the NHS. We have been pleased to offer advice and information to those involved with these initiatives. Some of them are summarised below.

The Medical Research Council

The Medical Research Council (MRC) is a publicly funded organisation with responsibility for funding and promoting medical and biomedical research in the UK. The Council has recently established a Consumer Liaison Group. This Group will advise on the best ways of promoting effective and appropriate support in the MRC's activities, and ensure that the MRC is aware of and able to respond to consumer interests and concerns about research. Members are consumers, researchers and those already involved with the MRC. *Consumers in NHS Research* offered advice to help to establish this group, and now has an ongoing relationship with members.

The Clinical Trials Unit of the Medical Research Council, which co-ordinates a number of trials funded by the MRC, has also developed its work to involve consumers. Consumers have been involved in HIV/AIDS trials co-ordinated by the MRC for some years. The MRC is now beginning to involve consumers in cancer trials by organising workshops for consumers to discuss both planned trials and the results of completed trials.

The UK Co-ordinating Committee for Cancer Research

The UK Co-ordinating Committee for Cancer Research (UKCCCR) is a forum for joint working and exchange of information amongst leading cancer charities. In October 1999 the UKCCCR held its first workshop to plan a Consumer Liaison Group. This Group, which will consist of cancer patients, carers, representatives from cancer support organisations and others will:

- advise the UKCCCR on appropriate ways of involving consumers in cancer research
- work with other UKCCCR groups to develop policy and guidance on consumer involvement
- advise on the recruitment of consumers to other committees/groups
- monitor consumer involvement and contribute to the evaluation of its impact

example 'd'

TRAINING FOR INVOLVEMENT IN R&D

The Voices in Action Project, funded by the Department of Health and based at the College of Health, aims to create a sustainable training and support scheme for lay representatives working with the NHS.

The project held interviews and focus groups with lay representatives, users, carers and statutory and voluntary sector staff to identify what sort of training and support is most needed and how it should be provided. A national collaborative conference was held to discuss preliminary findings.

There was overwhelming agreement about the key issues that need to be tackled if the government's aim of achieving a greater voice for consumers in health research and service delivery is to be turned into a reality. Recommendations included:

- Training and support should be inclusive, and be designed to enable a wide range of people to get their voices heard
- Training should reflect the diversity of consumers' needs and abilities
- To be effective, the context of the provision of training and support for lay representatives is critical
- There should be joint training with health professionals and training for health professionals on how to involve consumers, as well as joint training to promote effective collaboration

"If we're going to really involve people in a serious way that's got credibility then that does unfortunately have cost implications. It means that information has to be provided in a way that's accessible - that you've got to go at people's own pace, that you're respectful to people... and that takes time and costs more. But if you think about it, all research should do that anyway." (User Researcher)

The Alzheimer's Society

In the last year the Alzheimer's Society has launched a new research programme, *Quality Research in Dementia*. The major focus of the programme is to improve the quality of life for people with dementia and their carers.

QRD aims to match its research agenda to the real needs of people with dementia and their carers, actively involving them in setting priorities for research, selecting proposals for funding, monitoring ongoing projects and disseminating the outcomes of research. Through this programme, the Alzheimer's Society aims to influence the direction of basic scientific research, care practice, health and social policy for the benefit of people with dementia and their carers.

In order to ensure that consumers can play a full part in the work of QRD, the programme is developing special training for them. This will take place across the country throughout 2000.

The Toronto Group

We have been pleased to establish links, through staff at the *Consumers in NHS Research Support Unit*, with the Toronto Group. This group consists of consumers and researchers in health and social care. Its aim is to enhance the role of consumers in research and to promote research as an empowering process.

The Toronto Group organised a seminar on consumer involvement in partnership with the National Institute of Social Work earlier this year and is planning to hold another seminar in the autumn, with funding from the Joseph Rowntree Foundation. A proposal is also being developed for a series of seminars to be held across the country in 2001.

Links with the Toronto Group have enabled us to learn more about consumer involvement in research in social care, and to raise the profile of *Consumers in NHS Research* amongst researchers and consumers in the social care field.

"There's the difficulty of matching research with the fears people have about it and I feel one of the things we've got to try to do is to de-mystify and 'de-sophisticate' it... to try to get over to people that research is something they do maybe not daily but every time they plan a holiday or buy a fridge." (Researcher)

example 'e'

INVOLVING CONSUMERS IN RESEARCH IN AN NHS TRUST - THE IMPACT RESEARCH TEAM

At the Hull and East Riding Community Health Trust, staff and consumers have worked together to develop a research project. The project aimed to develop a transferable, flexible model for the evaluation of consumer involvement in NHS decision-making at clinical and corporate levels. This study was identified and prioritised by consumers who are also researchers.

The project is being undertaken using an action research method. The Impact research team includes mental health service users, managers, clinicians and researchers. Members of the team have received action research training through a bursary provided by the NHS Executive Northern and Yorkshire Region.

The study began in January 2000. The main learning from the process to date has been that mental health service users are quite capable of expressing their views if given the opportunity, but in order to bring about change, all stakeholders need to participate and contribute.

"It's not widely advertised that users can actually get involved in research and I think that people tend to think 'oh it doesn't matter what I say they're not listening to me anyway.' What the public need to know is that they are listening to you, so instead of sitting back and moaning in private, get up there and make your feelings known and then you will change things. Stand up and be counted!" (Consumer)

"The experience has been very important in terms of any research project - to actually spend time listening to and talking to the people that the research is about to make sure the research fits in with people's lives. Without that, we would be doing things that are totally wrong and not making a difference to people's lives." (Researcher)

3. Our plans for 2000/2001

During the coming financial year we aim to continue to work to achieve the objectives outlined in our Strategic Plan. Some of our planned activities are outlined below:

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

In June 2000, we will be holding a seminar for research commissioners and funders, in particular medical research charities and NHS regions, to promote shared learning and the development of consumer involvement in the research commissioning process.

During 2000/2001, we will continue to support the development of regional collaborations of consumers, researchers and research managers to increase the involvement of consumers in NHS R&D. We were pleased to note the funding awarded to Folk.us, the Forum for Collaboration with Users in Research, by the South West regional R&D Office. Folk.us, which is based in Exeter, aims to promote research that is relevant to the concerns and priorities of consumers.

We have also appointed a secondee on a part time basis for one year to promote the development of consumer involvement in NHS R&D in the four NHS regions in the north of England.

**Strategic Objective Two:
To empower consumers to become more involved in NHS R&D**

We recognise that some consumers need additional support, knowledge or skills to enable them to become more actively involved in health research. Over the past four years, we believe that we have begun to build some of the foundations through which consumers can be supported to become more involved in NHS R&D. However we know that there is much still to do in this area. During 2000/2001, we plan to ensure that our guide to R&D in the NHS is updated to

reflect the new strategic framework for NHS R&D, *Research and Development for a First Class Service*. We will also produce some guidelines for consumers who wish to become involved in health research.

In March 2000 we commissioned a team of consumers and researchers based at Exeter University to undertake a study on the ways in which consumers have been involved in R&D in other fields (such as social care, the environment and health promotion). This study will be completed during the financial year 2000/2001. Results of this research will be available on our website, and we will be using the knowledge we gain to inform our work and future plans.

Through our work to date, informal networks of people committed to the involvement of consumers in health research have begun to develop. We hope to promote this networking by providing information and support. April 2000 saw the launch of the Consumers in NHS Research website (www.hfht.org/ConsumersinNHSResearch), which enables those with access to the Internet to download all our publications and access the latest news and events relating to consumer involvement in health research. In the coming year we will continue to develop and promote this website as an aid to networking.

In April 2000 we also published our first newsletter, which aims to keep those interested in consumer involvement in health research up to date. It will be used to publicise innovative ways of involving consumers in research, as well as to encourage the development of networking in this area.

In 2000/2001 we will continue to develop a database of health research projects in which consumers have been actively involved. An initial database was developed in 1998 by researchers at the University of York. A second database, which focused on the involvement of those from black and minority ethnic communities in health research, was also undertaken in 1998. We will be updating and refining these databases over the coming year, with a view to making a version available through our website. We hope that this will encourage the sharing of experience and good practice.

During 2000/2001 we will also explore how we can best promote the training available for consumers to help them get involved in NHS R&D. We will also explore whether there is an appropriate

role for *Consumers in NHS Research* in the support of consumers who are members of research ethics committees.

**Strategic Objective Three:
To monitor and evaluate the effects of
consumer involvement in NHS R&D**

We recognise that it is important to assess the impact of consumers' involvement in health research, particularly as some researchers and policy makers require evidence before they will promote consumer involvement. During 2000/2001 we will continue to monitor consumer involvement in regional and national NHS R&D programmes, and to offer support and advice to those working in these programmes.

We will also undertake the second phase of our study on consumer involvement in organisations that receive R&D support Funding for NHS Providers. This will involve a small number of case studies of the ways in which NHS Providers are involving consumers strategically in their organisations and also in individual research projects.

Later in 2000 we will be holding a workshop for those researchers who are involving consumers in randomised controlled trials and the consumers who are collaborating with them. This will enable us to disseminate the results of our survey on consumer involvement in RCTs (see page 9) and to begin developing guidelines for researchers on involving consumers in this type of research.

We will also be liaising with the Health Services Research Collaboration at Bristol University who are undertaking an assessment of training opportunities in health services research. We hope to explore whether such training tackles issues related to consumer involvement.

We will seek to promote the inclusion of a question on application forms for funding issued by NHS R&D regional offices regarding whether consumers have been or will be involved in the research process for which funding is sought. In order to do this, we will be holding a workshop for staff in regional offices to develop standard questions. In addition, we plan to develop guidelines on how research funding bodies and peer reviewers could assess the quality of consumer involvement in research proposals and research reports.

In an attempt to begin to evaluate the impact of consumer involvement on R&D in the NHS, we have asked the Methodology Programme to consider funding some research, which would appraise methods for monitoring and evaluating the impact of consumer involvement in specific research projects.

"GOLD is a four year research programme looking at the needs of older people with learning disabilities. The idea was to ensure that the programme reflected what older people with learning disabilities were saying... What we've learned is that our ideas about what we wanted people to do were quite different to the people who were coming along to the group... It's a balance between the needs of the programme and what the people who come to the group are hoping for." (Researcher)

"I enjoy going to the GOLD Group. I get paid for it. I talk in conferences. The group is friendly." (Consumer)

example 'f'

INVOLVING CONSUMERS IN PALLIATIVE CARE RESEARCH

In July 1999, the first national seminar on involving service users and improving quality in palliative care was held, supported by the Joseph Rowntree Foundation. It was jointly organised by a group of palliative care service users, workers and researchers from St John's Hospice, London; Middlesex University; the Macmillan Runcie Day Hospice and the Centre for Citizen Participation, Brunel University.

The aim was to make it possible, for the first time, for a group of people often considered too ill or incapacitated, to take part in the formulation of policy and research. A primary aim of the seminar was to involve service users in a process of agenda setting to identify priorities for research, as well as for policy and practice.

A mixture of service users, professionals and policy makers attended the seminar, with service users in the majority. Both conceptual and practical barriers to involving people who are very ill, and might not have long to live, were discussed.

Service users present felt it was very important to have more opportunities to meet and be involved. They showed they were able to work together, given suitable support, and able to think in policy and research terms - as well as offering insights for how practice might be improved and they could be involved more.

Overall, the day was very successful. It showed that people with life threatening conditions are eager to participate and can make valuable contributions - and that with imagination and commitment, many of the practical problems previously thought to preclude their involvement can be overcome.

Further regional events and follow up initiatives involving service users are planned.

A short report of the seminar is available from the Centre for Citizen Participation at Brunel University.

4. How to contact us

Please do get in touch with us if you would like more information about the work of *Consumers in NHS Research* including:

- copies of our publications
- information about forthcoming events
- help and advice about involving consumers in your research if you are a researcher
- help and advice about getting involved in research if you are a consumer

You can contact *Consumers in NHS Research* through our Support Unit. Contact details are as follows:

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

Tel: 01962-872247

Fax: 01962-831947

E-mail: conres@hfht.org

Website:

www.hfht.org/ConsumersinNHSResearch

Appendix One

Consumers in NHS Research

Terms of Reference

Consumers in NHS Research was set up by the Director of Research & Development in 1996, and is a sub-group of the Central Research & Development Committee. *Consumers in NHS Research* aims to ensure that consumer involvement in research and development improves the way that research is prioritised, commissioned, undertaken, disseminated and used. It will:

1. Develop and promote alliances among key groups, including consumers, researchers, research funders and those in the NHS in order to promote consumer involvement in R&D
2. Promote the empowerment of consumers in becoming more involved in R&D in the NHS
3. Monitor consumer involvement in NHS R&D, in particular in the wider work of the CRDC and its sub-committees
4. Encourage the evaluation of the effects of consumer involvement in NHS R&D
5. Report regularly to the CRDC, and make recommendations about the development of consumer involvement in NHS R&D

Appendix

Two

Consumers in NHS Research

Membership 1999-2000

Chair:

- Ruth Evans, National Consumer Council (to June 1999)
- Nick Partridge, Terrence Higgins Trust (from June 1999)

Vice chair:

- Harry Cayton, Alzheimer's Society
- Carol Baxter, Middlesex University (to March 2000)
- Jane Bradburn, College of Health
- Peter Cardy, Multiple Sclerosis Society
- Elizabeth Clough, NHS Executive Trent Region
- Vikki Entwistle, Aberdeen University
- John Gabbay, National Co-ordinating Centre for Health Technology Assessment
- Bob Gann, the Help for Health Trust (to March 2000)
- Diana Garnham, Association of Medical Research Charities
- Russell Hamilton, NHS Executive South West Region
- Valerie Harrison, NHS Executive Eastern Region (to June 1999)
- Tony Hope, ETHOX, Oxford University (to March 2000)
- Debra Humphris, NHS Executive South East Region
- Julie Jones, Westminster City Council (to February 2000)

- Alastair Kent, Genetic Interest Group
- Maggie Rastall, Greenwich Community Health Council (from June 1999)
- Caroline Woodroffe, freelance health service researcher (to March 2000)

Observers:

- Val Billingham, Patient Partnership Strategy Co-ordinator (to September 1999)
- Steve MacKenney, Patient Partnership Strategy Co-ordinator (from September 1999)
- Joan Box, Medical Research Council
- Elizabeth Mitchell, Medical Research Council

