Involving consumers?

An exploration of consumer involvement in NHS Research & Development managed by Department of Health Regional Offices

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EXECUTIVE SUMMARY

This study examined the nature and extent of consumer involvement in research activity managed by the Department of Health regional offices. The work was carried out by the Consumers in NHS Research Support Unit on behalf of Consumers in NHS Research.

During 1999 we interviewed key individuals within the eight NHS Regional R&D offices, to explore consumer involvement in NHS R&D Regional Programmes, and examined the annual reports produced by NHS service providers receiving Support Funding (e.g. hospitals and primary care groups).

Consumer Involvement in Regional R&D Programmes

The study found there to be limited consumer involvement in the R&D Regional Programmes. However, most regions were developing plans to involve consumers further (an update of activities within the regions since the visits can be seen in the appendix). The main ways in which regional offices were involving consumers were in prioritising and commissioning research, with all but one of the regions involving consumers in this way.

Five of the regions had involved consumers on committees to prioritise and commission research, and in three regions, consumers had been involved in consultation exercises relating to prioritisation. The other main way in which consumers were involved in commissioning was in peer reviewing (3 of the regions had involved consumers).

Interviews with regional staff highlighted that they had different interpretations of the terms ‘consumer’ and ‘involvement’, which influenced the way in which regions responded to the policy commitment to involve consumers.

Whilst most of those interviewed supported the principle of consumer involvement, some were more convinced than others of the value of involving consumers.

The key concerns centred around identifying who were the most appropriate consumers to involve and how best to involve consumers effectively. These concerns related to choosing ‘representative’ consumers and / or ensuring that a balanced consumer perspective was obtained. Views differed on the type of consumer who should be involved and whether or not consumers needed to represent a wider group, or be chosen for their individual experience and / or perspective.

Views also differed on whether there was the need to support consumers through training, with some expressing concerns that training and involvement could make consumers less ‘representative’ of the general public. However, it
was generally agreed that new members of committees needed some form of induction to enable them to participate effectively.

**Consumer involvement in R&D Support Funding**

Across the eight regions there were a total of 282 NHS Providers receiving Support Funding during 1998 / 1999. Annual reports were available on 248 of these Providers. The detail available in these reports varied considerably and thus it was often difficult to determine the extent or nature of consumer involvement. These findings should therefore only be seen as a rough indication of the nature of consumer involvement.

Just over two fifths of the Providers (42%) reported that consumers were involved in some way in the R&D activities of the Trusts.

In 12% of Trusts, consumers were involved strategically or on committees, in 21% of Trusts, consumers were involved in individual projects or initiatives, and in 9% of Trusts they were both involved strategically, and/or on committees and specific projects or initiatives.

As in the Regional Offices, involving consumers on committees was the most frequently cited method of involving consumers strategically, with nearly half of the representatives being from Community Health Councils.

Consumer involvement in individual projects included clinical trials as well as qualitative studies, and spanned a wide range of stages in the research process. Involvement in planning and design were most frequently cited.

**Conclusion**

There was no general consensus across the regional offices as to what was meant by consumer involvement, whom should be involved, and how best to involve consumers. This was reflected in the variation in the extent and nature of consumer involvement across the regions. This report suggests that all regions should have a designated contact for consumer involvement and that a consumer involvement strategy should be developed in order to achieve a consistent approach.

Although those interviewed were, in the main, positive about the potential value of consumer involvement, some expressed reservations about the ability and resources to support involvement, and the need for research evidence on the value of consumer involvement. There is a role for Consumers in NHS Research to further support the regional offices as well as to develop plans to support evaluations of the effectiveness of involvement.
Recommendations for:

The Central Research and Development Committee

- It seems important that the terminology and the approaches used by all regional offices should be consistent. In order to achieve this we suggest that the definition of ‘consumer involvement’ provided by Consumers in NHS Research is endorsed by the Central Research and Development Committee. (See page 42)

Regional Offices

- Definitions of ‘consumer’ and ‘involvement’ need to be clearly stated on guidance for Providers receiving Support Funding. This guidance can be developed in partnership with Consumers in NHS Research. (See page 42)

- Regional offices should encourage discussion and networking between Providers receiving Support Funding. This can be achieved in partnership with the Consumers in NHS Research Support Unit. (See page 44)

- There needs to be the opportunity for a joint learning process between those working in Regional Offices and Consumers in NHS Research, in order to develop more innovative ways of involving consumers in the future. (See page 43)

- The process of involving consumers may be enhanced by including a minimum of two consumers on appropriate committees. (See pages 45 & 47)

- It may be useful to think about gaining a consumer ‘perspective’ rather than having a consumer ‘representative’. It may also be worth involving a wider spectrum of people. A ‘job description’ can be used to recruit people with the right skills to committees. (See pages 45 & 47)

- Consumers who take part in research should be provided with training and support to help them feel able to participate. (See page 47)

- Regions that are involving consumers should monitor their involvement and communicate with consumers. It is important that consumers are provided with an opportunity to give feedback about involvement from their perspective. This is likely to improve the way consumers are involved in the future. (See page 47)
• All Regional Offices should have a designated person responsible for consumer involvement. Support should be made available to this person to help them to develop consumer involvement. (See page 48)

• A consumer involvement strategy across the eight regions should be developed. (See page 48)

Consumers in NHS Research

• A short document should be developed targeted at Providers receiving Support Funding to illustrate ways in which consumers can be involved and provide examples of specific initiatives being undertaken in regions. This will be informed by the next phase of this study which will provide case studies of Providers that are involving consumers. (See page 44)

• The Consumers in NHS Research Support Unit will continue to provide support to the regions. The addition of a Northern Development Manager (seconded to Consumers in NHS Research) has helped to provide support to the four more Northern regions. Consumers in NHS Research could also facilitate meetings. (See page 48)

• Consumers in NHS Research should encourage plans to support evaluations of the effectiveness of involvement. (See page 48)
4.1 THE VALUE OF INVOLVING CONSUMERS .............................................. 17
  4.1.1 Ensuring research is relevant to consumers .................................. 17
  4.1.2 Providing a different perspective .................................................. 18
  4.1.3 Ensuring the research addresses the ethical concerns of patients .................................................. 19
  4.1.4 Encouraging service users to participate in research .................. 19

4.2 RESERVATIONS ABOUT INVOLVING CONSUMERS ......................... 19
  4.2.1 Who to involve – identifying appropriate consumers .................. 20
  4.2.2 ‘Professional’ consumers versus ‘members of the public’ ............... 22
  4.2.3 The usefulness of consumer involvement .................................... 23
  4.2.4 Commitment to consumer involvement ....................................... 24

4.3 VIEWS ON CONSUMER INVOLVEMENT AT THE DIFFERENT STAGES OF THE RESEARCH PROCESS ........................................... 24
  4.3.1 Identifying and prioritising research ............................................ 24
  4.3.2 Commissioning .......................................................................... 26
  4.3.3 Dissemination / lay summaries .................................................... 28

4.4 CONCLUSION ................................................................................... 28

5. CONSUMER INVOLVEMENT IN R&D SUPPORT FUNDING FOR NHS PROVIDERS ........................................................................... 30

5.1 BACKGROUND .................................................................................. 30

5.2 LIMITATIONS OF THE STUDY ......................................................... 31

5.3 THE EXTENT OF CONSUMER INVOLVEMENT ................................. 32
  5.3.1 No involvement of consumer / not enough information ............... 34
  5.3.2 Planned involvement .................................................................... 35
  5.3.3 Strategic / committee involvement ............................................... 35
  5.3.4 Involvement of consumers in individual projects or initiatives ........ 37

5.4 CONCLUSION ................................................................................... 40

6. DISCUSSION AND RECOMMENDATIONS ........................................... 41

6.1 BACKGROUND .................................................................................. 41

6.2 DEFINITIONS OF ‘CONSUMER INVOLVEMENT’ ............................... 41
ACKNOWLEDGEMENTS

We would like to thank Elizabeth Clough and Russell Hamilton for all their help and advice in planning this study and Bec Hanley for her useful comments on earlier drafts. We are also very grateful to those people we talked to in the Department of Health regional offices, for giving up their time and providing us with so much useful information.
1. INTRODUCTION

1.1 BACKGROUND

Since 1991 the NHS has been running a programme of Research & Development (R&D). This aims to provide decision-makers in the NHS with reliable and relevant information, which is based on research. Consumers had already played an important role in some areas of R&D in the NHS, but there was room for improvement. Recognising this, the Central Research and Development Committee (which advises the Director 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, called Consumers in NHS Research*, met for the first time in 1996. Consumers in NHS Research believes that the involvement of consumers in the research process leads to research that 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 that can be used to improve practice.

One of the objectives of Consumers in NHS Research is:

“To monitor & evaluate the effects of consumer involvement in NHS Research & Development.”

In 1999 a small Support Unit was set up at the Help for Health Trust to support the work of Consumers in NHS Research. In working to achieve the above objective, the Consumers in NHS Research Support Unit was asked to undertake a study to examine the nature and extent of consumer involvement in research activity managed by the regional offices. The study examines consumer involvement in NHS R&D and Support Funding for NHS Providers managed by Department of Health regional offices. The study was undertaken during 1999 and an update of activities (as of August 2000) can be found in the appendix.

* Formerly known as the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme.

1.1.1 NHS R&D managed by Department of Health regional offices

Each of the eight NHS R&D regional offices manages a number of research programmes carried out in their regions. These all vary, but most regions have some or all of the following:

- A commissioned programme
  To fund research and development which is identified as being a priority by the Regional Director of R&D.

- A responsive programme
  To provide funds for which researchers can apply with their own ideas.
• A training programme
  To help people (usually those working within the NHS) become more skilled in research and development through training and support

Although programmes within regions vary, those managing the process are involved in similar tasks, including deciding on priorities for research programmes, commissioning and managing research and ensuring that research provides the anticipated outputs in terms of dissemination of findings.

1.1.2 R&D Support Funding for NHS Providers

In addition to the Research Programmes, the Regional Offices administer R&D Support Funding for NHS service providers (e.g. hospitals, primary care groups and community trusts). This funding enables Providers to support their own research programmes, as well as to cover any extra costs to the NHS as a result of their involvement in non-commercial research that is usually paid for by external funders (such as the Medical Research Council or medical research charities).

1.2 LAYOUT OF THE REPORT

Section 1 provides an introduction to the study, the aims and the methods used.

Section 2 briefly examines definitions of ‘consumer’ and ‘involvement’, and attitudes towards the use of terminology.

Section 3 examines how consumers are being involved in the work of regional offices.

Section 4 looks at the attitudes of those working in regional offices towards involvement, the successes they have experienced and their reservations.

Section 5 examines the information provided by analysing information in the Annual Reports from NHS Providers receiving Support Funding (1998/1999).

Section 6 provides a discussion of the findings of the report and draws together the conclusions. It also provides a number of recommendations on how we can improve the nature and extent of consumer involvement in the future.

The appendix provides an update on activities in the regions since the original visits for this study. It shows that 18 months later there have been considerable advances in terms of initiatives being undertaken.
1.3 AIMS OF THE STUDY

The study aims to:

- provide an understanding of the ways in which consumers are involved in R&D managed by the regional offices
- identify the obstacles and opportunities for effective consumer involvement
- build links with regional offices and NHS Providers and
- encourage future involvement of consumers in research.

1.4 METHODS

1.4.1 Interviews

Interviews were carried out between August and October 1999, with respondents from the Regional R&D Offices who are responsible for overseeing the work of the R&D Programmes and R&D Support Funding for NHS Providers. In most cases one R&D manager was interviewed from each regional office, but on a couple of occasions two people were present for all or some of the interview. The interviews were carried out by Sarah Gorin and Sarah Buckland from the Consumers in NHS Research Support Unit.

The purpose of the interviews was to explore the nature of consumer involvement. The interviews explored the approach of the regions to consumer involvement in research, views on the nature and extent of consumer involvement, and ways in which the Consumers in NHS Research Support Unit can assist or work with the regions to further develop consumer involvement.

Analysis of the interviews examined the ways in which consumers have been or are being involved in the activities of the regional offices and the views and attitudes of those interviewed towards consumer involvement.

The interviews were semi-structured, using a topic guide. Prior to the interviews the topic guide was sent to Russell Hamilton, Director of R&D South West and Elizabeth Clough, Deputy Director of R&D Trent for comment. The interviewees were sent a copy of the main topics to be covered in advance of the interviews. The interviews were tape recorded and transcribed. The transcripts were analysed using NUDIST (a computerised qualitative analysis tool) and framework analysis (Ritchie and Spencer, 1994) The interviews were analysed by themes to explore the range of views expressed by the interviewees. Summaries of the factual information about the activities of the regional Research and Development Directorates were sent back to those interviewed for checking.
1.4.2 Documentary information

Information available within the Regional Offices was examined to explore the nature of consumer involvement both within the R&D Programmes and R&D Support Funding. This included a review of the annual reports from recipients of R&D Support Funding in all the regions. In the case of involvement in the R&D Programmes this included an examination of any documentation relating to guidance for grant applicants in involving consumers, as well as any policies on consumer involvement in prioritising, commissioning and dissemination of research.

1.5 CONFIDENTIALITY

Regions are named in the report in relation to practical initiatives that have been undertaken to involve consumers. Information with regards to these initiatives is already in the public arena but has not previously been drawn together nationally.

 Regions are named in relation to practical initiatives undertaken by Providers receiving Support Funding for NHS Providers, however individual names of Providers remain anonymous.

As agreed in the interviews with respondents, any views expressed during the interviews are also anonymised in this report.
There has been and still remains a great deal of confusion and disagreement amongst those in health and related fields about the use of terminology when for example, describing the involvement of patients or long term users of services in research. In order to avoid confusion in the interviews with regional respondents the definitions used by Consumers in NHS Research were provided. These are as follows:

‘Consumers’ are defined as:

‘Patients, potential patients, carers, long-term users of services, 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.’

Consumer ‘involvement’ is taken to mean:

‘active involvement of consumers in the research process, rather than the use of consumers as ‘subjects’ of research.’

Respondents did not all agree with the definitions used by Consumers in NHS Research, nor had they all ascribed the same meanings to ‘consumer involvement’ in the past. Several respondents expressed confusion and/or dislike for the term ‘consumer’. Two alternative interpretations of consumers were given:

- Consumers of the work produced by R&D programmes are usually other researchers or professionals working within the NHS
- Everybody is a potential consumer of NHS services

An example of the former interpretation was that the term ‘consumer’ was misleading because consumers of research were often other researchers and health professionals and not patients, carers etc. For this reason one respondent preferred to use the term ‘public involvement’:

‘... consumers is a completely confusing terminology. As far as I am concerned, as far as the R&D Regional Offices, and the national R&D programme our consumers are actually researchers in the NHS, not the public. And this is about the public presumably, and patients. So they are not our consumers, they are the NHS’ consumers, they are not ours. So it’s somewhat meaningless, probably an American derived term.’

Another respondent reiterated this when asked about using consumers to peer review proposals:
‘Q. Have you used consumers at all in peer reviewing proposals?
A. No. I mean it depends very much how you define consumers, doesn’t it. I suppose if you’ve got research done with GPs then GPs are the consumers, but they are not the public.’

The second interpretation discussed by respondents was that many people are consumers of NHS services and most people may need to use NHS services at some stage.

‘…what is a consumer, you know? Because in some areas, some of the wider areas, I mean, we are all consumers aren’t we?’

There was also confusion about the use of the term ‘active’ involvement of consumers. For example, one respondent did not feel that consumers were necessarily actively involved in their research programmes, although the views of consumers were reflected in their work. The R&D programmes were informed by the results of consultation with consumers undertaken in other sections of the regional office. In this way, the region was not directly involving consumers but was using the results of consumer consultations undertaken by others in the locality.

A recent paper circulated after a workshop with CHC members and lay members of ethics committees in the Eastern region, highlighted that despite a definition of ‘consumer involvement’ being provided by Consumers in NHS Research there was still considerable disagreement and concern about the terminology and the underlying values of involvement.

The understanding respondents had about ‘consumer involvement’ was reflected in the way in which they responded to the need to involve consumers and the way in which they perceived the role of the regional office in furthering consumer involvement in research.
3.1 BACKGROUND

This section looks at the ways in which consumers were involved in NHS R&D managed by DH Regional Offices, as well as future plans for consumer involvement. It is organised by examining the types of initiatives that have occurred at the different stages of the research process.

3.2 IDENTIFYING AND PRIORITISING RESEARCH

There were two main ways Regional Offices had tried to involve consumers in identifying and prioritising research topics. These were:

- consumer membership of committees and
- consultation about priority setting, either using workshops or questionnaires:

One Region said that consumers were not involved in priority setting as they used national priorities, and so it was not appropriate for consultation to take place at regional level.

3.2.1 Consumer membership of committees

The Regional Offices all have slightly different committees to manage R&D Programmes. However, all of the regions have at least one committee that operates as a strategic advisory committee, and most have one or more other committees to manage the different aspects of the programme (e.g. responsive research, commissioned research and bursaries). Identifying and prioritising research could therefore occur within any of these different committees. For example, prioritising could occur in the strategic advisory committees, to decide on the overall direction of the programme, and within commissioned programmes to decide on specific research topics. The table below (see Table 1) summarises where consumers are or have been involved in the various committees. Only five of the eight regions had consumer involvement on one or more of their R&D committees at the time of the interviews. Three of these regions had consumer representation on their strategic advisory committees (Northern & Yorkshire, Trent & West Midlands). Only one of the Regions reported having a committee where there was more than one consumer member.
<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Current consumer involvement</th>
<th>Committee</th>
<th>Who involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>No</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>London</td>
<td>Yes</td>
<td>Main R&amp;D Committee</td>
<td>No consumer representation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Organisation Management Committee (commissioning)</td>
<td>One CHC representative</td>
</tr>
<tr>
<td>North West</td>
<td>Yes</td>
<td>Main funding committee</td>
<td>No consumer representation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Research &amp; Development fund (previously the Reactive &amp; Development &amp; Implementation funding schemes) – 3 zonal groups</td>
<td>Two of the groups - CHC representative One group – a consumer representative known to the group</td>
</tr>
<tr>
<td>Northern &amp; Yorkshire</td>
<td>Yes</td>
<td>Strategic Advisory Committee</td>
<td>Two CHC representatives</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Commissioned Research Committee</td>
<td>One CHC representative</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Capacity Committee</td>
<td>One CHC representative</td>
</tr>
<tr>
<td>South East</td>
<td>No</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>South West</td>
<td>No</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Trent</td>
<td>Yes</td>
<td>R&amp;D Council</td>
<td>One lay member – identified through personal contact</td>
</tr>
<tr>
<td>West Midlands</td>
<td>Yes</td>
<td>Regional R&amp;D Advisory Committee</td>
<td>One member of CHC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Commissioning committees</td>
<td>No consumer representative</td>
</tr>
</tbody>
</table>
3.2.2 Consultation on prioritising research

Three of the regions reported on initiatives that had consulted consumers about their priorities for research (see Table 2):

South West region reported on an exercise carried out in 1997 when questionnaires were sent to Trusts, Support Units, GPs, and Local Authorities to help prioritise research. Although only a couple of voluntary organisations were contacted directly, respondents were asked to consult with others and so may have had discussions at a local level with a wider audience that could have included consumers.

The North Thames Inner City Health R&D Programme (now subsumed under the London region), commissioned the College of Health to hold focus groups with users of services as part of a priority setting exercise.

The third regional office that reported consulting consumers about research priorities was Northern & Yorkshire. Two activities had taken place within the previous twelve months. The first was a study that involved: i) a questionnaire survey and ii) focus groups, to explore consumer views on priority setting. Respondents were asked: what questions they would like to see answered by research and development; what they thought should be the research priorities; which groups of people in the population they thought should be studied by researchers; and which medical conditions should be studied. The survey identified three main priority areas: cancer, mental health and heart disease. Elderly people were seen as the first priority group for research, and general practice as the area of service delivery most in need of research. As part of developing the latest call for the commissioned programme, a workshop for older people and organisations that work with and for older people was held. This workshop identified research priorities that were fed back to the commissioning group. At the time of the interviews a subsequent workshop was planned for researchers to develop the priorities into research questions.
Table 2: Identifying and prioritising research

<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Nature of involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>• None</td>
</tr>
<tr>
<td>London</td>
<td>• Focus groups held with users of services to identify priorities for research</td>
</tr>
<tr>
<td>North West</td>
<td>-</td>
</tr>
<tr>
<td>Northern &amp; Yorkshire</td>
<td>• Questionnaire survey and focus groups with users to identify research priorities</td>
</tr>
<tr>
<td></td>
<td>• Workshop with and for older people to identify research priorities (1999)</td>
</tr>
<tr>
<td>South East</td>
<td>-</td>
</tr>
<tr>
<td>South West</td>
<td>• Questionnaire survey on research priorities, suggestions for research funding and views on research capacity and infrastructure – questionnaires sent to Trusts, Support Units, GPs, &amp; Local Authorities. Only a couple of voluntary organisations contacted directly. (1997)</td>
</tr>
<tr>
<td>Trent</td>
<td>• None</td>
</tr>
<tr>
<td>West Midlands</td>
<td>• None</td>
</tr>
</tbody>
</table>

Although East Anglia (now subsumed under the Eastern region) had not involved consumers in identifying and prioritising regional work, they had involved consumers in 1992, as part of the national research programme, by holding a workshop to identify research questions on physical and complex disabilities. Voluntary organisations representing people with physical and complex disabilities were present at this workshop, and contributed ideas about what they felt needed to be researched. East Anglia submitted the piece of work to the national programme.

3.3 COMMISSIONING RESEARCH

As can be seen from Table 1, four of the regions had consumer representation on committees that commissioned research (London, North West, Northern & Yorkshire and Trent). In the London region, the consumer representative on the commissioning committee was leading the discussion on one of the priority areas being considered.

3.3.1 Peer Review

Three of the regions had involved consumers in peer reviewing grant applications (Eastern, London and South West), although the extent and regularity of use was variable (see Table 3). Regions that had used consumers to peer review tended to do so when they felt a proposal had
particular implications for consumers rather than using consumers as peer reviewers on a routine basis.

### Table 3: Other consumer involvement in commissioning process (apart from representation on committees)

<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Nature of involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>• Has used voluntary organisations for peer reviewing</td>
</tr>
</tbody>
</table>
| London                | • CHC representative leading discussion on one of the priority areas being considered for commissioning  
                         | • CHC representative peer reviewing proposals                                           |
| North West            | • None                                                                                  |
| Northern & Yorkshire  | • None                                                                                  |
| South East            | • None                                                                                  |
| South West            | • Some grant applications sent to appropriate user groups for peer review               |
| Trent                 | • None                                                                                  |
| West Midlands         | • None                                                                                  |

### 3.3.2 Grant Applications

Four of the eight NHS Executive Regional Offices (Northern & Yorkshire, Trent, South West and West Midlands) had introduced or were about to introduce guidance to encourage research applicants to involve consumers in their research projects in the R&D Programme (see Table 4).

Trent introduced the requirement to involve consumers as part of their application form for the Trent Research Scheme in 1999, South West introduced the requirement in the summer of 1999, and in the Northern and Yorkshire region it was to be introduced in the next round of commissioning. All three regions asked whether or not the applicants had consulted / involved consumers, and if not why not. None had made this a condition of funding, although all three stated that applicants would need to provide reasons as to why it was not appropriate to involve consumers. In the West Midlands Region, the guidance for the Locally Organised Research Scheme requires that applicants who chose to involve consumers, must indicate how they will be involved, what impact their involvement will have, how users will be remunerated and what is required of the users at each stage.

Trent have started to analyse the extent to which applicants addressed the consumer involvement question on the application form for the responsive funding scheme. They found 49 of the 95 applicants (52%) had addressed consumer involvement. Of these, Health Services research was most likely to address the issue (23 out of 31 responses) and Laboratory research the least
likely (7 out of 28 responses). Clinical research fell in between the two (19 out of 36 responses).

**Table 4: Consumer involvement in grant applications**

<table>
<thead>
<tr>
<th>Region</th>
<th>Research Programme</th>
<th>Consumer involvement Questions / Guidance</th>
<th>When implemented</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>London</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>North West</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern &amp; Yorkshire</td>
<td>Responsive and Commissioned funding applications</td>
<td>Applicants are required to indicate by ticking boxes on a sheet (included with application form) how many different criteria for funding they have addressed (9 criteria). One of these criteria is whether users or carers are involved.</td>
<td>To be introduced for next round of commissioning</td>
<td>No plans for monitoring / evaluation</td>
</tr>
<tr>
<td>South East</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| South West      | Responsive R&D, and Developments in the Organisation of Care, Project Grants Schemes (not Commissioned R&D) | Guidance notes for applicants state that in assessing applications the Committee will take account of consumer involvement. It will consider; 

  *The level of involvement in the planning, conduct and/or monitoring of the project by service consumers.*

  (One of 5/6 criteria) | Introduced beginning of Summer 1999 | Next year, level of consumer involvement may be monitored as one of the outputs. |
<table>
<thead>
<tr>
<th>Region</th>
<th>Research Programme</th>
<th>Consumer involvement Questions / Guidance</th>
<th>When implemented</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trent</td>
<td>Research &amp; Development Project Grants</td>
<td>Grant application form asks: Have you consulted consumers about this project? Yes / No If yes, please describe below If not, please say why not</td>
<td>1 year ago</td>
<td>Started to evaluate the extent of use of this question on the application form, as well as the content of what was written.</td>
</tr>
<tr>
<td>West Midlands</td>
<td>Locally Organised Research Committee (responsive scheme)</td>
<td>Where consumer involvement is appropriate, details are to be provided on how consumers will be involved, the impact of their involvement, how users will be remunerated and what is required of users at each stage. (Informal guidance)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.4 MANAGING RESEARCH

None of the Regions mentioned involving consumers in the process of managing the research that was funded. It appears that this was considered to be an administrative task of the regional offices to ensure that the work was carried out and completed as agreed.

### 3.5 DISSEMINATION

The research respondents were asked whether they had involved consumers in dissemination. Only one region reported involving consumers in dissemination, through their publication of Bandolier (Table 6). In discussions with regions, consumer involvement in dissemination was usually taken to mean that information should be presented in a way that was easy for consumers to understand, rather than consumers actively disseminating research information.
### Table 6: Dissemination of research findings

<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Nature of involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>• Contributes to funding and distribution of Bandolier, which has some public involvement.</td>
</tr>
<tr>
<td>London</td>
<td>• None</td>
</tr>
<tr>
<td>North West</td>
<td>• None</td>
</tr>
<tr>
<td>Northern &amp; Yorkshire</td>
<td>• None</td>
</tr>
<tr>
<td>South East</td>
<td>• None</td>
</tr>
<tr>
<td>South West</td>
<td>• Grant applicants are asked how the research will be disseminated. This might included targeting consumers or carers.</td>
</tr>
<tr>
<td>Trent</td>
<td>• None</td>
</tr>
<tr>
<td>West Midlands</td>
<td>• Research applicants to the Locally Organised Research Scheme are asked to outline how they intend to disseminate the results of their research to consumers (where appropriate).</td>
</tr>
</tbody>
</table>

### 3.6 OTHER INVOLVEMENT

Table 7 below summarises some of the other activities undertaken by the regional offices that have involved consumers.

### Table 7: Other involvement

<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Nature of involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>• None</td>
</tr>
<tr>
<td>London</td>
<td>• Provided feedback to Support Funding recipients about the consumer involvement performance indicator and provided examples of activities of other providers (to promote good practice)</td>
</tr>
<tr>
<td>North West</td>
<td>• None</td>
</tr>
<tr>
<td>Northern &amp; Yorkshire</td>
<td>• None</td>
</tr>
<tr>
<td>South East</td>
<td>• Developing knowledge management for health programme that will include consumers in its development.</td>
</tr>
<tr>
<td>South West</td>
<td>• Contributed funding towards a regional conference on consumer involvement, for users, NHS staff, representatives and researchers (1999).</td>
</tr>
<tr>
<td>Trent</td>
<td>• None</td>
</tr>
<tr>
<td>West Midlands</td>
<td>• Contacted all other regions to identify consumer involvement activity around the country • Produced a paper about consumer involvement and its plans to take it forward in the region</td>
</tr>
</tbody>
</table>
3.7 FUTURE PLANS

All the regions had plans to involve consumers in the R&D Programmes in the future (see Table 8). At the time of the regional visits, West Midlands and Eastern Region were planning to hold seminars with local CHC representatives and other interested organisations in order to develop a plan of how involvement in R&D could be taken forward. Eastern Region have since held a workshop with members of CHCs and lay members of research ethics committees. North West Region were planning to set up a consumer reference group to carry out a similar consultation about how consumers want to be involved in R&D. Other possible plans for involvement included: hosting a workshop for those receiving Support Funding (London); consumers acting as peer reviewers (North West, Northern & Yorkshire and South East); improving involvement of consumers on committees (Northern & Yorkshire and North West); and involving consumers in dissemination of research (Trent). Northern & Yorkshire was considering creating a shadow research committee composed entirely of consumers that would feed into the main commissioned research committee.

Table 8: Future plans for consumer involvement in the Regional Offices

<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Nature of involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern</td>
<td>Consultation planned with CHCs and lay members of ethics committees in order to determine how they would like to be involved in R&amp;D. Held on the 13 January 2000 in Cambridge</td>
</tr>
<tr>
<td>London</td>
<td>May host a half day workshop for those who receive Budget 1 funding to share strategies for involving consumers</td>
</tr>
</tbody>
</table>
| North West      | Develop a consumer reference group to consult consumers about how to involve other consumers in R&D  
                  | To utilise a regionally based R&D Representatives network meeting to raise awareness within NHS Trusts and to organise a regional event  
                  | Lay membership on a peer review panel  
                  | Follow up consumer involvement performance indicator on the annual reports and encourage those receiving R&D funding to involve consumers in the most appropriate way  
                  | Find a suitable consumer representative for the R&D Committee  
                  | Speak to Patient Partnership lead about consumer involvement |
| Northern & Yorkshire | Series of meetings planned to explain to researchers what is meant by consumer involvement  
                   | Considering creating a shadow research committee to include people who attended the older people workshop  
<pre><code>               | Plans to involve consumers in reviewing grant applications |
</code></pre>
<table>
<thead>
<tr>
<th>Regional Office</th>
<th>Nature of involvement</th>
</tr>
</thead>
</table>
| South East      | • Consumers may be identified to review reports of research findings for the Mental Health Programme  
|                 | • May consider using consumers to peer review proposals  
|                 | • Review the performance of NHS providers in terms of mandatory performance indicators |
| South West      | • Review of R&D planned that will consider other possibilities for consumer involvement |
| Trent           | • May in the future require a lay summary as well as an executive summary from grant holders  
|                 | • Consider introducing seminars for lay people to disseminate results  
|                 | • Mapping exercise to identify and contact relevant user groups |
| West Midlands   | • Organising a seminar to discuss the involvement of consumers in R&D. The seminar will involve representatives from CHCs and other organisations |

### 3.8 CONCLUSION

Consumer involvement in activities managed by the R&D Regional Offices has until now mainly been limited to involvement on committees, peer review and individual prioritisation initiatives. However regions are beginning to think and plan other ways in which they can involve consumers. Several regions were arranging consultation exercises that would ask consumers how they would like to be involved in R&D.
The regional respondents were asked their views on the value of involving consumers in research. Responses were largely positive with most of the respondents suggesting that consumer involvement could improve the quality of research. However, although there was a general commitment to the principles of consumer involvement, putting this into practice appeared to be less straightforward. As will be shown later in this section respondents raised concerns over how to identify appropriate consumers, and how best to involve them, as well as the need to establish the ‘effectiveness’ and value of consumer involvement through demonstrating its’ impact on the research process. Some offices whilst embracing consumer involvement had reservations about some issues, whereas others who had involved consumers very little at the time of the interviews, appeared supportive of the need to involve consumers. This section seeks to highlight the range of views expressed by the regional respondents.

*Please note that this section reports on the views expressed by respondents during the interviews and are not necessarily the views of the Consumers in NHS Research Support Unit.*

**4.1 THE VALUE OF INVOLVING CONSUMERS**

Regional respondents were asked their views on the value of involving consumers in the research process. They highlighted how involving consumers in research could assist in four main ways:

1. Ensuring that the research was relevant
2. Providing a different perspective
3. Ensuring the research addressed the ethical concerns of consumers
4. Encouraging service users to participate in research

All of these are issues covered in a publication by the Consumers in NHS Research Support Unit as being reasons for involving consumers in the research process (Hanley et al, 2000).

**4.1.1 Ensuring research is relevant to consumers**

Many of the respondents expressed the view that consumer involvement can improve the quality of research carried out. They believed that consumer involvement was necessary to ensure that research was relevant to those people for whom the research was about, i.e. the patients:

‘... if your research is to improve health, it’s got to improve health for somebody, or some group of people. So if it’s to improve the health of
people with heart disease then you need to talk to people who represent people with heart disease, or people who know about people with heart disease, or people who have heart disease.’

‘...I think if you don’t involve consumers in designing research, you often don’t answer the question in ways that are convincing to the consumer about the results you get, or actually address the outcomes that are important, in terms of benefit, to the patient’

Similarly, two regional respondents commented that consumer involvement could help to prevent money being wasted on research that was not relevant, and to ensure probity in the use of public funds:

‘They’d contribute the same as everybody else would contribute, which is - I mean, they are there to advise on the content, direction, what we do in the regional research programme, and to add an element of probity on our spending of public funds.’

4.1.2 Providing a different perspective

Providing a different perspective on research was considered one of the major contributions that consumers made to the research process:

‘If consumers are involved, the people who are going to benefit by your research are involved right from the very beginning, they can often point out things to you that are really just common sense to a person suffering from the illness that you are looking at ... so it’s their experience that is a resource for the researchers’.

‘... giving us a perspective that we can’t have, sat here. So knowledge of the service from all different aspects of it.’

However, whilst acknowledging the different perspective provided by consumers, some of the respondents were less convinced that only consumers could provide this perspective, indicating that others could also provide a consumer perspective:

‘And I suppose what I would say is that we think about the consumer perspective as a set of values. So that in the same way as we would consider whether a research proposal was likely to be ethical, or that we would ensure that there were arrangements in place to reassure us that the research would be ethical, so that we would say that one of our other values would be relevance to consumers and importance to consumers. ... but I would emphasise that it is part of the value set that we have about research. And we expect all members of the ... panel to have those things in mind’

‘... All of the committee [is assessing whether the research is] good science, good value for money, whether it is something that is going to benefit patients generally, so they’ll all be looking at those general
things ... and I don’t see why a user can’t have a very valuable perspective, it’s equally valuable, but different ... I guess also that we need to have the sort of idea of the consumer perspective in mind when we appoint all the other people’

4.1.3 Ensuring the research addresses the ethical concerns of patients

The involvement of consumers in the research process was seen by some to provide a useful check on research projects, ensuring that researchers considered ethical issues in the design and execution of projects. One respondent felt that this was particularly important when dealing with sensitive topics.

‘... the other appropriate consumer involvement ... is obviously important in particular studies, in particular those involving interviews with the public, or with patients, or questionnaires, interviews, videoing, recording, anything like that which then impinges on research ethics ... Probably the most useful is in specific pieces of research which are particularly heavily intrusive’.

4.1.4 Encouraging service users to participate in research

The fourth way in which consumers were seen to be able to usefully contribute to the research process was in encouraging others to participate in research. Consumers could assist both in encouraging others to consent to participate in studies, as well as in improving compliance in research trials.

‘... they are often very important in increasing the acceptability of research protocols to those who are participating in research. And that can be as simple as how things are set out, designed and the layout. And about the language used, because it is very easy, even when you think you are very sensitive to trying to use simple language, to be unaware of, what to you are simple technicalities which the consumer has no comprehension at all’

‘You can sell consumer involvement on the back of better co-operation, better compliance, more likely to keep going if they’ve got an investment, you know if they’ve been involved right from the beginning ... ’
Regional respondents were asked if they had any reservations about involving consumers in research. The following section describes the main difficulties identified by respondents when trying to involve consumers.

The main reservations that regional respondents had about involving consumers were:

1. Identifying appropriate consumers
2. ‘Professional’ consumers versus ‘members of the public’
3. The usefulness of consumer involvement and
4. Commitment to consumer involvement

4.2.1 Who to involve – identifying appropriate consumers

The question of how to identify appropriate consumers was the most frequently occurring concern of regional respondents. Respondents raised theoretical concerns, particularly about how to identify the most appropriate consumers and also more practical issues, such as how to find out about different voluntary organisations, and finding people with the time and the necessary level of commitment. For example, some respondents raised concerns about consumers having the time to become involved in R&D and how this could lead to, what one person interviewed called ‘consumer fatigue’, where the same consumers get asked repeatedly to be involved in different initiatives:

‘In the first place, it’s difficult enough to find people from the health research community who have either got the time, the commitment, which I guess is part of the same thing, and actually be—it’s almost the social skills, to interact and involve themselves in contributing.’

Several of those interviewed, commented that in order to identify appropriate consumers it was important to be clear about what they wanted consumers to do before involving them:

‘It’s finding, trying to identify the task clearly enough that we would want them to do.’

Respondents in all the interviews raised the issue of ‘representation’. Views on the need for consumers to be ‘representative’ of the wider public varied. Respondents had different perspectives on who were the most appropriate consumers to involve and how they should be identified. The idea of ‘representation’ seemed to have led many of those interviewed to think about the way they should involve consumers and how to define a role they could effectively play. There were four main thoughts from respondents about who to involve. These were as follows:
• Consumers should be ‘representative’ of a wider body of people, presenting the voice of the ‘community’ to whom they are accountable.

Most of the regional respondents broadly supported this approach, i.e. that consumers should be accountable to a wider group. However, this still created concerns for some, about which groups or individuals should be contacted. Concerns related to the wish to find consumers who were able to give a view about a variety of different health topics, whilst at the same not being biased.

• Consumers should be chosen for their individual experience and ability to contribute a consumer perspective.

Views expressed often reflected a region’s previous experiences of involving consumers. For example one region had successfully involved a consumer in much of their work, but did not feel able to find anyone comparable to replace her when she left. However, several commented on how the current or previous consumers had added little to the debate and thus saw less value in involving consumers.

• Groups of consumers should be consulted e.g. through workshops / focus groups to ensure a broad consumer perspective is achieved.

Some respondents that were interviewed did not think it was possible to find a ‘representative’ consumer, because people are not ‘representative’ and their views will vary according to their own experiences. A solution given by one respondent was trying to involve larger numbers of people thus avoiding relying too heavily on one person’s advice:

‘and I don’t think you can do it – the representation. And I would like to see them involving larger groups in their processes…’

• The ability of a group to look at issues from a consumer perspective is more important than having consumers involved for the sake of it. Many people (not just consumers) can provide a consumer perspective.

A further view proposed was that consumers were not necessarily the only people who could provide a consumer perspective and that it was important for all involved in R&D to look at research from a consumer perspective.

Some respondents already felt that they were involving a ‘consumer perspective’ by having professionals consider the possible implications of research on patients’ experiences. Another region felt that it was unnecessary for them to undertake to involve consumers in their work, because they used the findings of the service development team to inform their priorities for research and the service development team had already consulted with consumers.
4.2.2 ‘Professional’ consumers versus ‘members of the public’

In discussing how to select consumers to involve in R&D, the issue of ‘professional’ consumers versus members of the public was sometimes raised. One view was that the same consumers were often used, and their contribution was diminished by their involvement with R&D because they were no longer able to see issues from the perspective of an ordinary ‘member of the public’.

Everybody’s so busy and I think, you know, the same way as in our home lives, it’s always the same people who are the school governors, who are on the social clubs and stuff, it’s very self-selecting. And as I first said, I wonder how representative people are. I mean, representation is a very difficult issue. I am fully supportive of the overlying principles of this work, because the main thing is really about appropriate services, which are not exploitative in any way. I’m not sure that there’s a simple answer in having a member of the public on every committee and group that we run.’

These concerns were also linked to practical issues about involving consumers, such as payment and training to enable consumers to take an active role. Respondents recognised the potential problems for consumers who are asked to become involved in the work of the regional office. It was recognised that committees can be daunting and consumers may not be able to understand some of the language used by professionals.

However, views about whether consumers should be provided with training varied. Some felt that it was important to provide training so that consumers felt able to participate fully in discussions, whilst others were concerned that training consumers may make them too ‘professional’. Some respondents believed that by training consumers you would make them ‘experts’ in the field and that you may lose something of their original thoughts in doing so.

‘..we’d want to explore, I think, what kind of training they might need if they were going to be on these lower level committees. Such that they can make a useful contribution and not be all sort of alienated by the sort of technical language …’

‘…. (she/he is) busy looking for ways to train consumers to take part – and I think if you do that, which the HTA programme did, I think you lose the viewpoint that you are seeking to include. Because they are no longer the average Joe Public. They are a member of a committee with knowledge and expertise, and I think you lose something there…’

Regional respondents had mixed views about consumer involvement and how to go about achieving successful relationships. Several of those interviewed felt that they did not have enough knowledge with regard to how to involve consumers and that this was particularly a problem when they themselves were approached for advice on involving consumers by people receiving funding from the regional office. A respondent said:
'My nervousness about putting it in (a question about consumer involvement on grant application forms) is the same as my nervousness that I’ve discussed with you in the past, about putting into a grant application form, a requirement to explain how they have involved consumers. And that is, that I would expect them to get on the phone to me and say ‘happy to involve consumers if you tell us how and to what end’ and I can’t tell them that.'

One region felt that those receiving Support Funding for NHS Providers were not necessarily adverse to involving consumers but they had not received formal guidance to help them understand how to go about it, hence it had not been addressed to the extent that it could have been.

4.2.3 The usefulness of consumer involvement

Some of those interviewed had tried involving consumers in different ways but not all had found it useful. This may have influenced their feelings about the value of involving consumers in future initiatives.

Views on ‘representation’ were linked to concerns about tokenism and how to avoid it. With regard to asking recipients of Support Funding for NHS Providers to involve consumers, one regional respondent said:

‘…we say we need something on consumer involvement so they produce it. But is it actually genuine or is it, as I say, ticking a box… you can see through some of these (annual reports)...where it is genuine and where it’s just, ‘they say we’ve got to do it, but we haven’t got any real enthusiasm for it but we won’t tell them that’… there’s a big cultural shift required.’

Another respondent thought that it was important not to have hard and fast rules about involvement:

‘What I wouldn’t do is to design a hard and fast framework for consumer involvement, by saying ‘thou shalt not have a research commissioning board without a consumer on it’. Because then I think what happens, is that a consumer is wheeled in to satisfy the requirement, and the consumer will sleep through most of the board meeting.’

Concerns were also raised about the lack of systematic research evidence to illustrate the ways in which consumer involvement can affect outcomes. Regional respondents tended to take the view that they would be more convinced about the value of involvement if there were some sound supporting evidence.
4.2.4 Commitment to consumer involvement

Consumer involvement was not seen as a key priority for some respondents that had to deal with the competing demands of an already heavy workload. There was the recognition that undertaking effective consumer involvement would take time and resources and these were not necessarily available. The time and resources were a key concern for some regional respondents who as discussed above, felt that there was no convincing evidence that involvement would improve outcomes.

4.3 VIEWS ON CONSUMER INVOLVEMENT IN THE DIFFERENT STAGES OF THE RESEARCH PROCESS

4.3.1 Identifying & prioritising research

Most respondents felt that it could be useful to involve consumers in identifying and prioritising topics for research. One respondent said:

‘There’s prioritisation, to know you are in the right areas, that they are relevant and this is what people care about out there….’

Most of those people interviewed were positive about the role consumers could play on committees:

‘I think some sort of issues such as … getting consent and those sort of things, I think her input’s quite helpful… I think she does – she has played a role, I think, a real role.’

‘…again for us having that real life angle on the research…’

However, several of the regional respondents appeared concerned that consumers would exert considerable influence and be providing comment from a very narrow perspective.

‘They must be representative in some way though…Because you can’t just have somebody who is or believes that we should be doing more cancer operations…and then persuades us that that’s what we should be – you know, doing more research into cancer operations by very persuasive arguments, you know, which are convincing. But on the basis of what are they saying all this? Then somebody down the road, or next door to them believes the entire opposite. You know what I mean, what’s the representation, they’ve got to have some kind of value, somebody’s got to sift and decide ‘this is the person who’s going to be representative of this community’. And that’s why I think the Community Health Council has to manage the process.’
Committee membership

The Regions that had involved consumer representatives on committees most commonly identified them through Community Health Councils (CHCs). It was because of concerns about consumers being representative, that many said that they used CHCs, as their consumer ‘representatives’.

‘Well I think they are aware of both sides of the coin. So I think that was part of the thinking behind having CHC reps to start with, to see how that worked out because they were likely to have had to deal with both types of organisation and to be aware of other organisations that might have a view on whatever the topic was that they were discussing at the time.’

However, a few of the regions did not think consumers had been particularly useful on committees. Three of the regions that had involved CHC representatives, found that they had not contributed as much as had been hoped. Respondents were unsure whether the lack of success was to do with individual ability to understand and participate in discussion, lack of strong views on discussions, or whether the committee itself did not enable consumer members to contribute:

‘I don’t recall the CHC person having a big input. You know getting up there you know. But I don’t know whether that’s because they don’t have a strong view on what we’re doing. Or, whether it’s because they don’t, you know, they don’t feel able to – in terms of their expertise, able to make those comments, but they have them. Or whether we just haven’t got the right representation on the committee, whether we need different representation.’

‘I don’t always think that committee membership is the appropriate way to involve consumers. Sometimes it may be, but it is a difficult thing to do because you may inhibit the progress of business, and you may not get full participation from your consumer reps because they might be inhibited by the fact that everybody round the table is a doctor apart from them.

Another possible reason given for consumers finding it difficult to contribute was the subject matter of the committee. There was some disagreement about the type of committees it is useful to have consumers on. One respondent thought that it would be most useful to have involvement at the level of an R&D advisory committee:

‘Probably the most useful involvement, I’m just thinking through off the top of my head really, further, would be at the advisory level where the R&D programme is meant to be ensuring the NHS determines the research it needs as an organisation…’

Others, however thought that it was not as easy for consumers to contribute to the business of an overall strategic advisory R&D committee as it might be
on a committee that deals with individual research projects. One respondent felt that decisions that went to the main R&D committee were often about funding and this was not something those without prior knowledge of the organisation could usefully have an input into. It was also felt that the committee could at times be just rubber stamping decisions.

A further issue raised, was consumer involvement on the responsive or generic research committees where grant applications could be received on a very wide range of topics.

‘On an ethics committee, or on a response led funding committee, or on, you know, even on an HTA panel, a diagnostics and imaging for instance, it’s very different (from a specialised research project) to find a consumer because you need somebody who will represent a generic consumer involvement, consumer perspective.’

Workshops to prioritise research

Several regions reported on initiatives to prioritise research where they had involved consumers. Views about the success of these were mixed, as were views about whether they were likely to be repeated in the regions. Some commented that consultation produced good ideas and had been helpful in moving the agenda forward, however, not all initiatives were thought to have been very useful. One key concern was that consumers tended to be more interested in problems relating directly to the service they had received rather than in discussing problems that could be turned into research questions. Thus for some it was felt to be difficult to engage consumers in research.

4.3.2 Commissioning

As discussed earlier, there were differing opinions about the effectiveness of the consumers on committees and their ability to contribute. One representative described an example of having a consumer on a commissioning group and what they had learnt about what a consumer representative was able to contribute:

‘There was a consumer involved there, that was somebody who actually worked in health care, but had been a breast cancer sufferer herself and a user of services for breast cancer treatment. And I think I learned from that that there was a real opportunity for a consumer perspective to influence that shape of the research agenda. But particularly, to shape the almost - not the design, but the specification for the research, to ensure that the right outcome measures were built into the research. Things like that.’

Another felt that as a member of the commissioning board, the consumer had the same influence as any other members and that their views about which proposals should be commissioned were therefore reflected in the decisions that were made.
Peer review

There was some interest in the idea of using consumers to peer review from the remaining regions, but several of those interviewed had reservations. The main concern of respondents when considering involvement of consumers in the commissioning process either through committees or peer review seemed to be not knowing what the role of a consumer should be and what they should be asking a consumer to contribute. There were also concerns about how to go about identifying appropriate consumers and that consumers may have their own priorities.

Several of those interviewed commented that some individuals might have a particular ‘axe to grind’ and that consumers may use the opportunity of involvement to advance their own research interests. For example:

..what we very often find is that the people (professional peer reviewers) we send these things to are enthusiasts for the topic, they think the topic is very important.. and what's working there is that they are giving the thing undue weight because of their view of the importance of the topic..... Now if we sent the application to a consumer, to a woman who may have that gynecological condition or to a consumer group that was representing women's views on gynecology, I would expect them to score it highly as well. Now I know there are all sorts of holes in that argument, but it is a problem, that you know, even NHS professionals have topics that are close to their hearts and therefore give them undue weight. Consumers, I think might be an even greater problem.

‘there's also a danger that if you get somebody from an organisation, a condition specific charity, that you'll get a campaigner, you'll get an advocate.’

Several of the respondents were not convinced of the value of involving consumers in peer reviewing proposals as they felt reviewers are usually expected to comment on the science of research and consumers were unlikely to have this level of expertise in research. It was felt that consumers may be able to contribute from a consumer perspective, but that using a researcher from a voluntary organisation may confuse the issue of what was expected of them and they were unsure that research knowledge was an advantage.
Grant Application forms

Three of the remaining regions that did not have consumer involvement as a question on their application forms explained that they would feel apprehensive about doing so until they felt sure that it would be useful:

‘I’d be reluctant to put more in the research application process than has been shown to be useful.’

The evaluation being undertaken by Trent may help regions to think about the benefits and difficulties with this approach.

4.3.3 Dissemination / lay summaries

Views were varied about the usefulness of lay summaries. Some of the regional respondents were in favour of the idea of developing lay summaries of research and thought they would be used by consumers and would give something back to research participants:

‘...when I’m talking about having abstracts in lay language- it’s partly so that I can read them, because I’m not medically trained, but you get a load of doctors together and they start talking in jargon and assuming that you’ve got knowledge you don’t have. And that is inhibiting. You realise that you are not at the same level of experience that they are ... there’s a lot of simple things people can do to make the experience of consumer involvement – it’s got to be – we want something from them, so we’ve got to give them something back...It’s very important to give feedback.’

However one representative was worried that lay summaries might oversimplify the findings of research, which could then be misinterpreted by lay people. Another view was that consumers with a particular interest in a health condition, technology etc. might want to read a whole research report and not just a summary.

4.4 CONCLUSION

Those interviewed were generally very positive about the value of consumer involvement, although views differed as to who should be involved and how they should be involved. Representation, tokenism and whether consumers should be trained were key themes that were discussed by respondents.
The perceived value of involving consumers as well as concerns about how best to involve consumers were all issues that have been raised by other professionals. Many of these issues have been addressed by a recent publication by the Consumers in NHS Research Support Unit (Hanley et al, 2000).

Consumer involvement was generally viewed as a small part of the work of the region, but one that was competing for time and resources. Its’ position in terms of priorities was not aided by the lack of good quality research evidence to support the use of consumer involvement. The lack of research evidence also meant that regions had developed disparate views about who to involve and how to involve consumers and their thinking had evolved largely in response to their own experiences of trying to involve consumers in individual initiatives. There was no general consensus across the Regional Offices on how best to involve consumers.
5. CONSUMER INVOLVEMENT IN R&D SUPPORT FUNDING FOR NHS PROVIDERS

5.1 BACKGROUND

Those receiving money through the R&D Support Funding for NHS Providers are subject to monitoring and annual review by the regional offices. Monitoring arrangements involve the setting of performance indicators. There are seven mandatory performance indicators and any number of agreement specific indicators. One of the performance indicators for the recipients of this funding is that Providers should by the year 2000:

… have developed a formal infrastructure for consumer participation in designing research, measuring outcomes of care and implementing research findings.

The late introduction of this performance indicator seemed to have caused confusion for some regions; one region in particular was unclear that it was a mandatory performance indicator.

The aim of this stage of the study was to gather documentary information from the annual reports for all the regions, in order to ascertain the extent to which NHS Providers were undertaking to involve consumers in their research. The information from annual reports was gathered at the same time as regional visits were undertaken (August - October 1999). The first annual reports from NHS providers under this system were submitted to regional offices in the summer and relate to the year 1998-99. However, the deadlines for submission varied between regions and at the time of the visits, some had not received annual reports from all those with a contract. In addition, some NHS providers had not commented on the consumer involvement indicator. The researchers attempted to gain the most up to date lists of those receiving Support Funding, but it should be noted that they might be slightly inaccurate due to annual reports having been submitted in the time that has elapsed between visiting regions and writing this report.

The data that was collected was entered on to the Statistical Package for the Social Sciences (SPSS) and analysed according to the type of consumer involvement, and the stage at which consumers were involved in the process. Any other interesting and innovative ways in which consumers had been involved were highlighted in order to gain an understanding of the range of different ways consumers are involved in R&D.
5.2 LIMITATIONS OF THE STUDY

Across the 8 Regions there were a total of 282 NHS Providers receiving Support Funding. Of these, 34 had not submitted annual reports to their regional office at the time of our visits. These Providers are not included in the following analysis of the data, as it is not known whether they have involved consumers in R&D. The data discussed will therefore be based on 248 Providers.

The information that was provided by examining the annual reports has limitations that should be recognised. Firstly, the information presented here relies solely on the information that Providers chose to submit in their annual reports. Some Providers clearly stated that they had not met the performance indicator whilst others did not write anything at all. Not all Providers who submitted annual reports necessarily wrote anything about consumer involvement. For example:

Patients were not specifically involved in R&D planning and delivery during 1998 to 1999. (South East)

Secondly, in some of those cases where information was provided it was very limited. There were examples of Providers writing a very general statement about consumer involvement, making it difficult to know whether they were doing anything specific to address the performance indicator. For example:

Patient involvement has been incorporated in our studies where appropriate. (East)

Thirdly, in some of the annual reports, definitions of the terms ‘consumer’ and ‘involvement’ may have been misinterpreted. The following is an example of the term ‘consumer’ being interpreted as a Primary Care Provider:

The need for consumer involvement is being met through: ……Collaboration with primary care providers in the local area…. (South East)

The interpretation of ‘involvement’ also seemed to have been misinterpreted by some Providers. Several reports described projects where patients seemed to have been involved as ‘subjects’ of research rather than as ‘active participants’ in the research process. For example one Trust provided the following as an example of consumer involvement:
Consumer involvement is proposed through the Care Development Programme ... the Health Psychology Team will develop questionnaires and patients will be interviewed within their homes about their experience of care. It is expected that this will direct and inform research activity into areas that are relevant to the care patients receive. (South East)

Some of the annual reports stated that consumer involvement was present in a number of studies and project titles were specified. In these cases we have assumed there was active involvement in the research process.

The range of information provided in annual reports did not make it easy to analyse and it should be noted that there was a degree of interpretation in deciding how to categorise activities being undertaken by Providers.

5.3 THE EXTENT OF CONSUMER INVOLVEMENT

The pie chart (see Figure 1) shows the ways in which NHS Providers who completed annual reports across the eight regions were involving consumers.

Just over two fifths (41%) of the Providers reported that consumers were involved in the R&D activities of the Trusts. Of this number 12% were involving consumers strategically or on committees, 20% were involving consumers in individual projects or initiatives and 9% were involving them both strategically and/or on committees and in specific projects or initiatives.

Almost three fifths (59%) had not involved consumers in their R&D. Of these the majority (49%) were either not involving consumers or did not provide adequate information in their annual reports to be able to identify involvement. A small proportion (8%) gave some specific plans for what they were intending to do in the future to develop consumer involvement. Providers were only included in the planning category if they had not done anything else to involve consumers and if they provided specific details of what they were planning. A very small proportion (2%) were not given consumer involvement as a performance indicator.
Figure 1: Pie chart to show the ways in which NHS Providers receiving Support Funding are involving consumers

This data can be broken down to compare the extent of consumer involvement currently being undertaken by those receiving Support Funding in different regions (see Table 8).

Table 8: Level of consumer involvement by NHS Providers by region

<table>
<thead>
<tr>
<th></th>
<th>Northern &amp; Yorkshire</th>
<th>South East</th>
<th>South West</th>
<th>East</th>
<th>West Midlands</th>
<th>Trent</th>
<th>North West</th>
<th>London</th>
</tr>
</thead>
<tbody>
<tr>
<td>No current involvement</td>
<td>16</td>
<td>27</td>
<td>10</td>
<td>13</td>
<td>18</td>
<td>14</td>
<td>12</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>57%</td>
<td>68%</td>
<td>43%</td>
<td>68%</td>
<td>86%</td>
<td>50%</td>
<td>41%</td>
<td>58%</td>
</tr>
<tr>
<td>Involving consumers</td>
<td>12</td>
<td>13</td>
<td>13</td>
<td>6</td>
<td>3</td>
<td>14</td>
<td>17</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>43%</td>
<td>33%</td>
<td>57%</td>
<td>32%</td>
<td>14%</td>
<td>50%</td>
<td>59%</td>
<td>42%</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>40</td>
<td>23</td>
<td>19</td>
<td>21</td>
<td>28</td>
<td>29</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>100%</td>
<td>101%*</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Column does not add up to 100% due to rounding
Table 8 shows the variation in the level of involvement across the regions. Included in the category ‘No current involvement’ were those Providers who were not involving consumers, did not provide enough information to establish whether they were involving consumers and those who did not have consumer involvement given as a performance indicator. Those ‘involving consumers’ were doing so either strategically or in individual research projects, or both.

The data suggests that some Regions had more Providers who were involving consumers than others. North West and South West Region had the highest proportion of Providers involving consumers. However it should be remembered that this might not be a true representation of what Providers were actually doing. Some Providers may also have received more encouragement than others to address the consumer involvement indicator in their annual reports. The data provided in the reports was qualitative and diverse and did not always fall neatly into categories.

It may be more useful to examine the range of ways in which Providers were involving consumers in the research process. The following section explains each of the categories used to analyse the data and provides an overview of the different ways in which Providers had involved or were involving consumers. This information can be used to provide some ideas of how Providers could seek to involve consumers in the future.

### 5.3.1 No involvement of consumers / not enough information

Responses were categorised under ‘no involvement/ not enough information’ if:

- information was simply not provided
- if Providers made a general statement which did not outline what they were actually doing or any specific plans or
- if information provided was not considered to be ‘consumer involvement’.

Almost half (49%, 121) of the Providers responses that were analysed came under this category. Some examples of these types of responses have already been given (see 5.2). It should also be noted that some responses from Providers in this category included requests for further information about how they should involve consumers. It was clear from reading the extracts from the annual reports that more guidance about how to involve consumers would be very useful:
The Trust recognises that it would benefit from guidance on how to involve service users in identifying priorities in R&D programmes. To ensure that this involvement is effective and appropriate would require some intensive work perhaps involving ethnographic studies. Such work is beyond both the skills and resources of the Trust and should perhaps best be adopted as part of a national R&D programme. (Trent)

This was also raised as an issue by some respondents from regional offices, who were unsure of how to advise Providers.

5.3.2 Planned involvement

A small number of Providers (8%, 19) gave specific information about what they were planning to do in terms of consumer involvement. Providers were only included in this category if they gave some specific plans and if they were not involving consumers in another way in R&D. Having a lay member on a research committee was the main way in which Providers intended to involve consumers (8 out of 19). The remainder planned to: make links with consumer groups and/or involve consumers in dissemination; involve consumers in specific projects; develop a strategy for consumer involvement; and set up a patients group which would consider R&D issues.

5.3.3 Strategic / committee involvement

A summary of the ways in which Providers have involved consumers strategically

- Membership of committees
- Question / lay summary on application form
- Consultation with CHCs to help prioritise and inform strategic planning
- Consultation with local patient and consumer groups about R&D strategy
- Development of consumer involvement policy for the Trust
- Review of consumer involvement in R&D in the Trust
- Conferences/ workshops to help inform priorities
- Consumer groups
- Strategy group to investigate how to involve consumers more actively in R&D strategy

Over one in ten Providers (12%, 30) specified information about involving consumers either on a committee or using consumers at a strategic level in developing or shaping policies.

The most common way of involving consumers in this category was through committee membership. Of the 41 Providers who gave information about consumer representation on committees, 16 said the lay representative was
from a Community Health Council (CHC), 23 stated they were from another source, such as a voluntary organisation and 2 had representatives who were from both CHCs and other organisations.

For example:

*The R&D Group has had formal patient representation since March 1998. One representative is currently a volunteer with the … Formal Advocacy project. This is very helpful in obtaining a user perspective on research and a ‘non-professional’ view, enabling the Group to see what we are doing looks like from the ‘outside’. (East)*

Five Providers stated that they had a question on their registration/application forms that asked researchers how they would involve consumers in the research or they asked for a lay summary of the research. The following was one example:

*An additional section has been added to the Trust Research Grant Application form entitled “lay summary”. It is supposed to encourage researchers to “focus on the patient”. (North West)*

Another method that had been used to involve consumers in R&D was consultation:

*Representatives of the …. (name )Support Group have been consulted in the development of the Unit’s strategy. (South East)*
5.3.4 Involvement of consumers in individual projects or initiatives

A summary of the ways in which consumers have been involved in individual projects / initiatives

- Priority setting and determining research questions
- Consultations with voluntary organisations in order to determine their priorities for research
- Co-applicant on research application
- Pre-protocol work before application submitted
- Involvement on project steering groups
- Consumers have influenced aims of research projects
- Planning and designing the research
- Advising on research methods and developing outcome measures
- Designing the research instruments (eg. questionnaire)
- Consumers been used to carry out research interviews
- Discussion of results with consumers
- Interpretation/ presentation of findings
- Consumers have helped to disseminate results by presenting at conferences
- Consultation with consumer groups
- Conferences / workshops
- Consumer groups have been set up that help consumers to get involved in R&D, generate research questions and advise on research ethics and consent, mainly for RCTs.
- The Trust records and monitors the level of consumer involvement
- Training for researchers is provided on consumer involvement in R&D
- The Trust newsletter is widely circulated with information about R&D
- A review of consumer involvement in the Trust has been undertaken for clinical governance
- The Trust have developed a database of voluntary organisations and the NHS regional office is going to write to them
- The Trust has used a survey to find out whether researchers within the Trust are aware of their consumer involvement strategy

Over one in five Providers (20%, 51) reported that consumers were involved in individual projects or initiatives, but not strategically or on committees. Providers did not always state how they were involving consumers or what type of research was being undertaken so it was difficult to obtain a picture of whether involvement in individual projects or initiatives was more prevalent in any particular type of research. There were examples, however, of involvement in clinical trials as well as projects which seemed likely to be more qualitative in nature. One Provider stated:

We have identified consumer involvement in a number of research programmes, including the …. (name) Foundation for Dermatological Research, breast cancer (nationally organised trials) Rheumatology (…) and Clinical Haematology (…).

We are conscious of the importance of appropriate lay/consumer input in the design of clinical trials. This has been shown to produce an added dimension of clinical relevance, improved focus on the outputs that matter to patients and better recruitment to randomised trials. The
Consortium will continue to make researchers aware of this and ensure that this performance indicator is included in the strategic planning of R&D programmes. (Northern & Yorkshire)

Some Providers did state the particular stage of the research project at which consumers were involved, and these can be seen in Table 9 below. Projects could be involving consumers in more than one-way so the total number does not represent the number of Providers. There were 37 providers in total who stated the stage of the research process at which consumers were involved.

### Table 9: Stage at which Providers are involving consumers in the research process

<table>
<thead>
<tr>
<th>Stage</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying topics</td>
<td>6</td>
</tr>
<tr>
<td>Prioritising</td>
<td>3</td>
</tr>
<tr>
<td>Submitting applications forms</td>
<td>3</td>
</tr>
<tr>
<td>Recruitment and fundraising</td>
<td>1</td>
</tr>
<tr>
<td>Planning</td>
<td>10</td>
</tr>
<tr>
<td>Designing</td>
<td>9</td>
</tr>
<tr>
<td>Undertaking</td>
<td>7</td>
</tr>
<tr>
<td>Managing</td>
<td>1</td>
</tr>
<tr>
<td>Disseminating</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>45</strong></td>
</tr>
</tbody>
</table>

One General Practitioners Surgery had used an imaginative way to consult consumers about research. They had used a notice board to ask patients to identify topics for research:

> During this year, through the practice notice board we have both informed our patients of the practice’s research activity but we have also asked for possible research ideas from the patients themselves. We are pleased that our patients have suggested some excellent ideas for research and these are being evaluated at present.

(South West)

Consumers were also being involved in the development of research proposals:

> ...a user has been involved in the pre-protocol work up for the osteoporosis project for submission to the project grants scheme.

(South East)

One way of involving consumers in research projects is by having them on a steering group and 6 Providers mentioned this as a way in which they were involving consumers:
For large R&D projects, appropriate patient representatives are invited to join the project steering group as named patient advisors. A clinical trial to evaluate the effectiveness of aloe vera in the treatment of stagnant leg ulcers exemplifies this. A patient who was used in the case study advises the steering group of patient issues.

(South East)

The annual reports show that consumers are being involved in the research process at a wide range of different stages. Of those who stated the stage at which consumers are being involved, the most frequent seemed to be in the planning and design stage. Three examples of consumers being involved in planning and design were as follows:

Two of the nine applications for research funding in 98/9 involved service users in the research planning process; one of these included a user as co-applicant. These are not token involvements but genuine research collaborations.

(Northern & Yorkshire)

There has been appropriate user and carer involvement in R&D planning and delivery. This has shown itself in a number of ways.

- First, the Trust as a whole has a major user involvement project and programme of work - ...(name of programme) – which raises the profile of user and carer involvement throughout the organisation.
- Second, there has been user involvement on the Trust-wide R&D Support & Communication Network from the outset, and this continues.
- Third, a number of research projects are centrally involved with user and carer views, and users have been involved in the planning and delivery of these. Projects in this category include the ‘family and substance misuse’ programme of work, the ‘family and schizophrenia’ work and the serious mental health R&D group...

(South West)

In this study individual users and carers were involved in deciding on how information gathering sessions for the research would be best run and helped to write the questionnaire.

(Trent)

In disseminating the results of research, one Trust wrote that a consumer had given a presentation of research results about newly developed diagnostic tests at an annual genetics conference. She was also due to make a similar presentation the following year to a different audience.
Some Providers also outlined other ways in which they were involving consumers in individual initiatives. These included establishing links with consumer groups and holding conferences and workshops with consumers. For example:

\textit{(The)Trust is running a series of seminars with ....University – on Developing the Research Agenda in Mental Health. Users are involved in the planning of this series. (They are) attended by service users, academics, commissioners & clinicians.} \hspace{1cm} (North West)

Some Trusts had set up consumer research groups that met to discuss and generate research questions. One large Mental Health Trust had such a group and they stated:

\textit{It is also planned that users will be involved in the execution of such projects, and the hypothesis that user research interviewers generate data with greater validity than non-user interviewers with identical training will be examined as part of these.} \hspace{1cm} (London)

\subsection*{5.4 CONCLUSION}

The information provided about consumer involvement in the annual reports from NHS Providers receiving Support Funding varied greatly. Some Providers did not write about the consumer involvement indicator at all, some wrote general statements of commitment and some provided more detailed accounts.

The absence of a structured approach from Providers made it difficult to provide an accurate picture about how much consumer involvement is taking place. Not only were there possible gaps in the data provided but it was also difficult to know whether the involvement described was involvement of active participants in the research process. The most that can be obtained from this data is an indication of the extent of involvement of consumers and some ideas about how they are involving them.

Just over two fifths of Providers (41\%) stated they were actively involving consumers either through committees, strategically or in individual projects and initiatives. However, this involvement may range from one person on a committee or involved in a project, to groups of consumers involved in a variety of different research activities. Examples were provided of consumers being involved at different stages of the research process from identifying topics for research to disseminating the results. Some of the projects were of particular interest as examples of consumers being actively involved in the research process. The annual reports will be of particular use in following up some of these interesting initiatives in the next phase of the study.
6. DISCUSSION AND RECOMMENDATIONS

6.1 BACKGROUND

This study provides a snapshot of the activities of regional offices and Providers receiving Support Funding. It draws together what has been undertaken in the eight regional offices in terms of consumer involvement and provides some of the views of people working in the regions about the successes and difficulties associated with involving consumers. It should be remembered that the views expressed in this study are those of a small number of respondents and may not be representative of the views of other people working within the regions.

The quality of the data supplied by NHS Providers receiving Support Funding in the Annual Reports (1998/99) was variable and meant that analysis could only be tentative. The main difficulty in interpreting the data was the vague nature of many of the responses. It was not always clear whether projects were actively involving consumers, as Providers often only stated the names and nature of projects ‘involving’ consumers and did not necessarily provide any information as to how they were being involved. It is difficult to make any generalisations because of the quality of the data, however the information does provide an indication of the extent of involvement and provides examples of the variety of ways consumers can be involved.

In March 2000, Lord Philip Hunt (Minister for Health) announced a new statement of policy and principles and a development programme to carry through reforms of NHS R&D (Department of Health, 2000). This means that the system of funding in R&D will change. However the issues raised in this report will remain relevant. There is a Government commitment to the involvement of NHS consumers in research and development and this has been endorsed by both Lord Hunt and Sir John Pattison (Director of NHS R&D). It will continue to be important that those receiving funding for NHS R&D are involving consumers in their work.

The following discussion will consider the key issues raised through undertaking this study.

6.2 DEFINITIONS OF ‘CONSUMER INVOLVEMENT’

As stated in Section 2, there is a lack of consistency across the regional offices in the use of the terms ‘consumer’ and ‘involvement’. Although Consumers in NHS Research have provided a definition of ‘consumer involvement’ (NHS Executive, 1999) this is not always known or agreed upon. It is not necessarily clear that the term ‘consumer’ when used within the research environment relates to consumers of NHS services rather than those who are the consumers of NHS research. Some of the Providers receiving
Support Funding also clearly found the term ‘consumer’ confusing and it was misinterpreted by some as health professionals or researchers. Similarly the initial monitoring undertaken in Trent region also highlighted that some researchers misunderstood the term ‘consumer’.

Some regional offices chose to use the term ‘consumer’, others did not. There is also confusion caused by the term ‘consumer’ in the sense that some saw everyone as a consumer of NHS services or at least a potential consumer. This led to the argument that everyone on committees can consider consumer involvement in terms of a value that should be addressed. Despite much debate, alternatives to the term ‘consumer’ are also problematic.

The use of the term ‘involvement’, meaning ‘active involvement’ was not always shared by some of those in regional offices and many Providers receiving Support Funding. Where possible, this report only details information about active involvement in research as defined by Consumers in NHS Research.

However, the way in which respondents in regional offices defined ‘consumer involvement’ did seem to be reflected in their views about the value of ‘involvement’ and the consequent development of practical initiatives in regions.

**Recommendations for:**

**The Central Research and Development Committee**

- It seems important that the terminology and the approaches used by all regional offices should be consistent. In order to achieve this we suggest that the definition of ‘consumer involvement’ provided by Consumers in NHS Research is endorsed by the Central Research and Development Committee.

**Regional offices**

- Definitions of ‘consumer’ and ‘involvement’ need to be clearly stated in guidance for Providers receiving Support Funding. Guidance on consumer involvement needs to be developed to accompany application forms for funding. This guidance can be developed in partnership with Consumers in NHS Research. The guidelines developed by Consumers in NHS Research (Hanley, 2000) should also help Providers to understand what is meant by ‘consumer involvement’ and how it can be achieved.
6.3 CONSUMER INVOLVEMENT IN THE NHS R&D REGIONAL PROGRAMMES AND SUPPORT FUNDING MANAGED BY REGIONAL OFFICES

6.3.1 Regional NHS R&D Programmes

The study has shown that at present there is limited consumer involvement in the R&D Programmes. The development of consumer involvement initiatives in the R&D Programmes has been sporadic and variable across regions. Variations in the development of consumer initiatives in regions seems to have been determined by: the success or problems associated with initiatives that have been undertaken in the past; time and resources available; and enthusiasm from individuals working within the region. Some regions were more convinced by the need and value of involving consumers in the R&D Programmes than others. Most of the involvement in the regions has been in prioritising topics and commissioning research and the main ways of involving consumers has been on committees or in workshops. Models of consumer involvement that have been developed (see Hanley et al., 2000) identify different types of consumer involvement in research. To date most involvement in the Regional Programmes is at the level of ‘consultation’ with consumers, as opposed to collaboration or user control.

Recommendations for:

Regional Offices

- There needs to be the opportunity for a joint learning process between those working in Regional Offices and Consumers in NHS Research, in order to develop more innovative ways of involving consumers in the future.

6.3.2 Support Funding for NHS Providers

NHS Providers receiving Support Funding for R&D are also at very different stages of developing consumer involvement. Over two thirds (42%) of Providers were shown to be involving consumers either strategically or on individual research projects. Examples of involvement spanned a range of different types of research, including clinical trials and there were a variety of methods and stages being employed to achieve involvement. Those Providers that stated the stage at which they were involving consumers most often said they were involving them in the planning and design of research. There was more variety in the type of involvement being employed than in regional offices and there were examples of consultation, collaboration and user controlled projects. Some Providers clearly had a better understanding and more experience of consumer involvement than others and people working within the regional offices did not always feel equipped with enough knowledge about consumer involvement to advise Providers.
6.4 EXPERIENCES OF INVOLVING CONSUMERS

6.4.1 Identifying consumers

Ways of identifying consumers for involvement varied, but consumers tended to be members of a CHC or people that were known to someone within the Regional Office. Those who were identified through contacts were often known to have the right skills to contribute effectively to a committee; whilst those identified via CHCs tended to have been recruited because they were expected to have the background knowledge and ‘represent’ a wider body. They were not necessarily identified because of previous experience of committee membership.

During discussions with people in Regional Offices the issue of who to involve and how to identify people was clearly one of the most contentious. There was a general view amongst respondents that somebody on a committee should be able to ‘represent’ the views of a wider number of people. This was the reason many of those in Regions had involved people from CHCs because they were deemed to have a generic knowledge of health services. However a ‘job description’ to ensure that people also had the right skills to participate on a committee had not been used in any of the regions. The guidance developed by Consumers in NHS Research (Hanley et al, 2000) addresses this issue. It should be remembered that all members of a committee will come with their own experiences and as such will have developed certain views. It is not only consumers who may not ‘represent’ a wider body, for example a doctor on a committee will not necessarily ‘represent’ the views of all doctors. To overcome these problems it may be useful to have two or more consumer members on committees and to think about finding people who can provide a consumer ‘perspective’.

Recommendations for :

Regional Offices
- Regional Offices should encourage discussion and networking between Providers receiving Support Funding. This can be achieved in partnership with the Consumers in NHS Research Support Unit

Consumers in NHS Research
- Develop a short document targeted at Providers receiving Support Funding to illustrate ways in which consumers can be involved and provide examples of specific initiatives being undertaken in regions. The next phase of this study will provide case studies of Providers that are involving consumers and will illustrate the different methods they are using.
Whilst involving members of CHCs on committees or in discussions seems to be the way many regions have been identifying consumers it should also be remembered that membership of a CHC may not always reflect the diversity of communities. There are other organisations that may also be able to provide a generic knowledge of health and they may be able to provide a different perspective.

‘Representation’ was not as much of an issue on condition or age specific committees. Some of those interviewed were concerned about having people on committees who would have very strong views about a particular aspect of the condition or treatment. However it can be argued that having people with a range of views and experiences can raise different issues and generate debate.

### Recommendations for:

**Regional Offices**

- It may be useful to think about gaining a consumer ‘perspective’ rather than having a consumer ‘representative’.
- Concerns about not having a range of consumer perspectives can be overcome by involving more than one consumer and by involving people who have contact with other consumers.
- Think about involving a wider spectrum of people, not just those from CHCs.

### 6.4.2 Successes and barriers to involvement

Experiences of involving consumers in the Regional R&D Programmes were mixed. Some people felt that involvement in committees, workshops and using consumers as peer reviewers was beneficial. Reasons given were that consumers can:

- ensure research is relevant;
- provide a different perspective;
- address ethical concerns and
- encourage other consumers to participate in research.

Where involvement of consumers had been viewed as successful, respondents felt that they had provided a valuable contribution and had raised issues that had not been identified by other members of committees or groups. Their involvement also helped in identifying and prioritising research that was deemed as important, thus ensuring research would measure outcomes that were not just important to professionals.

However not all involvement of consumers had been seen as successful. Views about involving consumers on committees and in workshops to prioritise research were varied. There seemed to be three possible
explanations for why some people found the consumer contribution more useful than others:

- It is possible that regional respondents had different expectations of what consumers would be able to contribute therefore their view of how effective they were differed.
- Some consumers were more skilled than others and therefore more able to contribute.
- The subject matter, environment and/or organisation of the initiative helped enable consumers to make an effective contribution.

Regional respondents were often not aware of whether consumers on their committees had received any support or training before attending meetings. There were mixed views about whether consumers should receive training, although it was generally agreed that new members to a committee should be provided with induction. The concern some respondents had was that providing training may make consumers too ‘professional’ and that this may mean they forget their previous perspective. It is important to think about the reasons for involving consumers. If consumers are to be part of a research committee the skills that they have to participate will be very important. These people may not be ‘typical’ of the general public but will be able to contribute consumer perspectives as well as access and present a range of consumer views.

Respondents who were critical of the consumers’ contribution in meetings appeared not to have followed this up with the consumers concerned. The input of consumers has not been monitored in any of the regions and in those regions where consumers had played a direct role there seemed to have been very little feedback from the consumers about how they perceived their involvement and the experience of being involved. Communicating and supporting consumers is very important and is likely to improve relationships and the contribution consumers are able to make. Entering committee meetings, particularly as the sole consumer, can be a daunting and disempowering experience. Previous experience of groups such as the National Childbirth Trust highlights that a single consumer representative on a committee can be seriously disadvantaged and that it can be an isolating experience in which consumers do not feel enabled to contribute. Only having one consumer also means that there will be no consumer presence on the committee if that person is unable to attend.

Only one Region had involved more than one consumer on a committee, despite the guidance of the Central Research and Development Committee (CRDC) that advises at least two consumers be included on committees.

Other documentation including the Department of Health’s ‘Maternity Services Liaison Committees – guidelines for working effectively’ (1996) suggests that consumers make up a minimum of a third of the core membership of a committee.
6.5 IMPROVING CONSUMER INVOLVEMENT IN THE FUTURE

At the time of our visits to Regional Offices (August-October 1999) most regions were developing plans to involve consumers. Some of the plans being developed will mean that consumers have a valuable input into the work of the Regional Office. For example, the development of a user advisory group in the North West will ensure consumers have an input into decision-making. Other regions are involving consumers in peer review or introducing consumer involvement on their grant application forms. It is hoped that Consumers in NHS Research will be able to work together with regions in order to promote shared learning. For example, Consumers in NHS Research is developing guidelines on how research funding bodies and peer reviewers can assess the quality of consumer involvement in research proposals and reports. This initiative could be usefully explored with regions.

In terms of future consumer involvement in regional work, some people had reservations. These reservations generally included questions about:

- the value of involving consumers and
- taking on the extra work required in order to involve consumers properly and avoid tokenism.

Some respondents in the regions felt that they would like more evidence of the benefits of involving consumers before developing detailed involvement. There also seemed to be uncertainty amongst some Regional Offices as to what approach to take, what type of activities consumers should be involved in, how to go about involving consumers and who to involve.

At present Regional Offices operate different systems of dealing with consumer involvement and a person with knowledge and responsibility for consumer issues is not always easily identifiable. London Region has a member of staff working on developing Primary Care R&D but who also leads...
on consumer involvement. Having an easily identifiable person with the lead on consumer involvement should make communication easier and will mean they will be able to develop their knowledge base and provide advice to others.

Respondents tended to have little experience of consumer involvement and several recognised that they did not know a great deal about the experiences of other regions in terms of successes/difficulties in involving consumers either generally or in specific initiatives. For those who did not have consumer involvement as a specified area of their work, it was another additional responsibility that they had to fit in without adequate time and resources.

Plans for future involvement within regions were generally being developed independently and there still seemed to be little co-ordination or communication of these plans between regions. Sharing experiences of consumer involvement between the regions seemed to be lacking and there appeared to be a need for a regular form of communication between regions about consumer involvement. Although the CRDC clearly endorses the idea of consumer involvement through the funding of Consumers in NHS Research, there is no requirement for regions to be actively involving consumers. It would seem that there needs to be a firmer commitment made to consumer involvement and the development of a strategic approach in order to address these issues.

As a result of this study members of the Consumers in NHS Research Support Unit have met with and started to develop working relationships with people within the regional offices. It is hoped that we will be able to continue to improve these relationships and work together to support consumer involvement.
Since visiting the Regional Offices and writing this report there have been important developments in the regional offices to further the involvement of consumers in R&D. This section (updated in March 2001) provides an update of activities and has been written in collaboration with representatives from the regions. The initial visits to the regions and the addition of Sue Straughair (seconded to Consumers in NHS Research Support Unit to work specifically with the more northern four regions) has led to an increased level of activity and the growth of partnerships between the regional offices and Consumers in NHS Research.

**EASTERN**

The Eastern region held a consultation workshop with members of CHCs and lay members of ethics committees in January 2000. It is anticipated that a similar form of consultation will be repeated at the beginning of 2001. The region will also be reviewing the information contained in the Trust's Annual Reports for relevant references of consumer involvement.

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**LONDON**

A number of developments have taken place to support consumer involvement in R&D commissioning in London. These include:

- The requirement for grant applicants to describe plans for involving consumers as partners throughout the research process and to justify non-involvement where this is proposed. However, consumer involvement in developing grant applications and conducting and managing research is a prerequisite for funding for the Primary Care Studies Programme. Applicants to all Programmes must also now include a ‘plain language’ summary for review by consumers, practitioners and other non-research experts. Applications failing to include a ‘plain language’ summary will not be considered for funding.

- The EQuIP (Effectiveness and Quality in Involving the Public) collaboration has been commissioned to contribute to a new Capacity Development Programme to support consumer and community involvement in all aspects of NHS R&D. EQuIP will design and implement training to build consumer confidence and skills in research related decision-making and practice. Discussions are also underway with Professor Patrick Pietroni with a view to incorporating a research module into the ‘Preparing Professionals for Partnership with the Public’ Programme. This dimension of the Capacity Development Programme will ensure that researchers and others already involved in commissioning, conducting and managing...
research are enabled to work in effective partnership with consumers. It is intended that EQuiP and Patrick Pietroni’s team will provide joint training to mixed teams of consumers and researchers.

- Plans are also underway to develop a pan-London Consumer Involvement Network. This will provide a mechanism for facilitating contact and partnerships between researchers and consumers who have been trained and supported by the Capacity Development Programme. Consumers involved in the new Programme of primary care studies, which will begin in September, will constitute the network’s early membership and be the first to benefit from the Capacity Development Programme.

Consumers have also been involved in a number of other regional initiatives. For example, London’s new primary care research agenda was agreed following 33 local priority setting exercises, most of which involved consumers. All those involved in local projects were subsequently invited to a regional Consensus Development Conference at which the criteria for funding primary care research was agreed. This included the requirement for consumers to be involved as partners throughout the research process, including developing full grant applications. In order to support this, a workshop was held in December 2000 to enable prospective grant applicants to identify how consumers could become involved. The strength of consumer involvement in each of the 126 outline proposals submitted to the Programme in February 2001 formed part of the quality key criteria for inviting full grant proposals.

The R&D Programme for London's Health identified the need for research into models of citizens and consumer involvement in health services planning as a commissioning priority. A specialist commissioning group has been convened, membership of which includes members of the public who were invited to participate through the London print media.

London’s Organisation and Management R&D Group has recently commissioned Imperial College School of Medicine to undertake a study entitled ‘Optimising user involvement in the planning and delivery of health care: Evaluation of models used by mental health services in London’. The Steering Group for this study includes representatives from consumer organisations, including user-led forums, MIND and ‘Survivors Speak Out’.

A project is also underway to identify the most appropriate infrastructure for developing and co-ordinating learning disability research across London. Service users have been consulted throughout the process and the Project Steering Committee, which is chaired by Dame Fiona Caldicott, includes user and carer members.

Nicola Woodward has lead responsibility for developing consumer involvement in R&D in the London Regional Office.

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NORTH WEST

The NHS Executive North West is currently involved in an initiative to encourage the 'consumers' of the NHS service or 'users' to become more involved in the research process. This means the active involvement of consumers, not as the subjects of research but to work in partnership to influence decisions on what research should take place and what questions are asked, influencing how research is undertaken, how the results are interpreted and ensuring the results are used in practice.

A Regional User Advisory Group has been established to work with the NHS Executive to develop a strategy to encourage users to be involved in NHS Research. The membership of the established steering group is varied consisting of consumer representatives that possess an R&D background ie. Non Executive Trust members, CHC members, members of the Patient Partnership Group, some North West R&D Managers and some attendees of the Consumers in NHS Research conference held in January 2000.

The Terms of Reference of the User Advisory Group are:

- To facilitate the development of a User Group that will contribute to the entire research process including prioritising, commissioning, undertaking, disseminating and using research.
- To identify barriers and opportunities to involving users in NHS R&D.
- To develop strategies to bring about organisational and cultural change within the NHS and partner agencies that will encourage user involvement
- To work with the NHSE and partner organisations to establish methods of identifying training and support needs of users and of researchers and to ensure that the means of providing these are available.

The terms are subject to change as the nature of the group is dynamic, critical of its own membership and evaluated to ensure continued relevance and effectiveness.

'How Can We Involve Users in Research? A Participatory Event for User Groups, Researchers and R&D Managers

The NHS Executive North West held three one-day Conferences in November / December 2000. These events were an opportunity for users of services, researchers and the NHS to work together to learn, and develop ways to improve user involvement in Research and Development.

The events were oversubscribed approximately 60 people attended each event, one-third of attendees were users. The evaluation forms were very positive and reflected the growing enthusiasm and awareness of user involvement in the North West. A summary of the key points raised was circulated to all attendees shortly after the events this will be followed by a full conference report in 2001.
'Making it Happen: Action Planning or User Involvement in Research and Development' Workshop

A facilitated workshop is currently being arranged to develop an action plan around the main themes from the conference. The Regional User Advisory Group and conference delegates who expressed a wish to become involved will work with the NHS Executive in moving the strategy forward.

Further Developments

**Application Forms**
The application forms for the R&D Training Schemes have been amended to encourage users to apply and also encourages applicants to involve users in their research projects.

**Bursary Scheme**
Health Service Users who wish to become involved or who are already involved in Health Services Research are invited to apply to undertake a taught course in Health Services Research Methods.

**Training Fellowship Scheme**
The Training Committee takes account of whether users have/will be involved in Fellowship projects, although this is not a condition of funding. Applicants must give details of how users have been consulted/will be involved. If users have not been involved the applicants must state reasons.

**North West R&D Support Unit**
The NWRDSU is a collaborative venture between the Universities of Lancaster, Liverpool and Salford and is funded from the NHS Executive North West budget. The Support Unit runs a series of courses addressing various aspects of Research eg. Introduction to R&D, Statistics etc. It is planned that a user ‘strand’ be developed as part of these workshops to encourage researchers to involve users at all stages of the research process. It is also expected that workshops specifically designed for users be developed.

**User Involvement in Committee Membership**
A member of the User Advisory Group sits on the R&D Training Committee
A member of the User Advisory Group represents a user perspective on the CHD/Stroke R&D network

**Future Plans**

- To look at how the regional office can inform NHS organisations to encourage user involvement.
- To encourage users to become involved through training, empowerment etc.
- To look at further changes required at the Regional Office, across all Directorates.
- To develop and publish a strategy
• To work with the Consumers in NHS Research Support Unit to further the strategy
• Engage conference attendees into the work of the User Advisory Group as a 'reference group'.

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NORTHERN AND YORKSHIRE

Following the information given in Annual Reports (1999/2000) from organisations which hold research funding contracts with the Regional Office, RO staff are meeting with key individuals within organisations to support the development of Consumer Involvement Strategies for each organisation. Examples of good practice are being compiled within the Regional Office. These examples are being used to encourage wider information sharing between organisations and the development of supportive networks in this area.

In partnership with Consumers in NHS Research, an event was held in November 2000 that brought together an audience of researchers to hear examples of best practice from consumer organisations within the Region. The discussion again aimed to promote understanding of the issues relating to consumer involvement and encourage positive policy formation in this area.

Trusts throughout the Region are currently preparing draft R&D Training Strategies. The emphasis of these documents is on the full range of R&D training from foundation to advanced level. It is anticipated that many of these documents will make reference to both researcher and consumer training requirements in terms of consumer involvement and identify resources and inputs that are required to facilitate this process.

Many Trusts and Health Service Organisations within the Region have active working groups with user involvement looking at the best model for user involvement across the full range of organisational activity. R&D is one small section of this agenda, but is benefiting from these wider discussions surrounding organisational culture development of consumer involvement. Different departments of the Regional Office share information regarding user involvement developments in R&D, Clinical Governance and quality contexts. The sharing of this information will become more formalised via the arrangements for the implementation of the National Plan. One Trust/University partnership is currently undertaking a series of action research projects around key service delivery issues which contribute to an overarching research project into consumer involvement. Consumers are involved at every stage of the individual projects and the overarching study.

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SOUTH EAST

A seminar on consumer involvement for Lead Research and Development Officers was held in the South East region in June 2000. The seminar aimed to provide a forum for discussion about how consumers can be involved in research and development. Representatives from NHS Trusts, voluntary organisations and social service departments in the region gave talks to small groups about their experiences of involving consumers. The discussions highlighted a number of key issues including how to identify consumers, training and support for consumers and professionals, and the need for additional resources.

The regional office also plans to run a series of seminars for consumers during Spring 2001 to assist consumers in understanding the operational management of research in the NHS.

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SOUTH WEST

The South West region is supporting the development of consumer involvement in the region by providing funding for a collaboration of users and researchers (Folk.us) based at Exeter University. The funding supports a programme of activity intended to improve consumer involvement in research. This programme is supported by a co-ordinator.

In addition they have a number of research projects which are either involving researchers or in one case they have funded a user to do some research. Finally the R&D Support Funding Annual Reports for 1999/2000 have indicated that in some NHS organisations in the South West there is a lot of work going on in the area of consumer involvement including examples of jointly professional/user-conducted research and an example of research conducted and led by a user.

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TRENT

The R&D Group in Trent region held an event on consumer involvement in November 2000 at the Denewood Centre, Nottingham. Following this event they produced a leaflet summarising the lessons learnt at the conference and their intentions for the future. For example they are going to:

- Disseminate guidance produced by Consumers in NHS Research.
- Offer support through networking. They have a database of consumers who have offered their help and together they will support the R&D community. More volunteers are always welcome. Please contact them if you are interested.
• Target future events to specific groups of people e.g. separate seminars for consumers and researchers.
• Request that all future applicants, who apply to them for funding should include a lay summary in the proposal using non-technical language, and no jargon.
• For the Supporting Research Careers R&D Scheme they are involving consumers who will oversee the shortlisting process with other health professionals. This will be managed by post and/or email instead of holding meetings. The leaflet is on their website http://www.nhsetrent.gov.uk/trentrd/rd.html

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WEST MIDLANDS

The West Midlands Regional Office is developing a consumer involvement strategy. The strategy includes developing two databases, the first of which will record R&D contacts in Trusts and other health organisations in the region. The second will record consumers and consumer groups with an interest in the field. They are also considering introducing lay summaries of research proposals as part of their strategy for consumer involvement in the application process. The region held an event in the autumn of 2000 (with Consumers in NHS Research) to launch their strategy and provide a forum for discussion about consumer involvement in R&D. They are planning a further regional seminar in spring / summer 2001 to develop the strategy further.

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REFERENCES


