

**The Impact of Health Service Policy on Research and Development
Activity in NHS Trust Research & Development Offices:
A Survey of Research & Development Offices in England 2005/2006**

Mary Cooke¹ and Virginia Minogue²

¹ University of Manchester

² Bradford District Care Trust

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Abstract

An electronically managed survey of NHS Research and Development (R & D) managers was conducted in 2005-2006 by the NHS RD Forum Service User and Carer Working Group. The study aimed to identify the location for the responsibilities, and the levels of public, service user, and carer involvement in the annual workload of Research and Development Offices in England. The study also aimed to identify the current trends underlying the context of public and service user involvement in research and determine initial findings that could be utilised for comparison in further studies. The questions posed by the study were:

- that public and service user involvement in research is an increasing part of the current context of health service research, and,
- that public involvement in research is supported by resources as part of the research management and governance responsibility.

The study had a response rate of 24% (n=76) from the total number of R & D offices in England (315). From the responses, it was clear that aspects of Government guidance and policy, relating to the involvement of the public, service users and carers in NHS health services planning, administration, participation in and dissemination of NHS health and social care services, were being implemented. This survey provides an indication of the levels of involvement of the public and service users in research. It pointed to an inverse relationship between the level of dedicated resources and the actual support for public involvement activity. Those research managers who supported the highest levels of activity generally had fewer dedicated resources.

Key words: Research and Development offices; service user involvement; resources; support; policy.

Introduction

Government health policies and guidance, published since 1996, have increasingly promoted public and service user involvement in all aspects of health service planning and development (Department of Health 1998, 1999, 2001, 2001a, 2001b, 2004a, 2004b, 2005). This means that service users and carers have been encouraged to become members of NHS Trust boards and committees. Lay representation is a feature of NHS Research Ethics Committees, professional bodies and regulatory authorities among many other statutory groups (Department of Health: 'The NHS Plan' 1999).

Similarly, health service research has followed the path of service user involvement with publications of various papers such as 'The Expert Patient' (Department of Health 2001), and the formation of a Department of Health development and support group INVOLVE, encouraging further involvement of the

public in health services and social care and public health research (www.invo.org.uk). The Research Governance Framework for Health and Social Care (Department of Health 2005) also underlines the importance of involving service users and carers in the governance and design of research. Research commissioners are now expected to acknowledge the realities of public involvement in research to varying levels. Funding sources for public and health service research such as The Medical Research Council (MRC), and the Economic and Social Research Council (ESRC) all now have a 'service user and carer' representative group as part of their decision-making board. The National Institute for Health Research (NIHR), the main commissioner and support mechanism for NHS research, also requires service user involvement in research applications and at review stage as part of their bidding process for research funding.

Many charity-based research funding sources now have a similar representation on their board, but not all. Large funding management committees such as The Sainsbury Foundation for Mental Health Studies or Cancer Research UK accommodated this policy early in the trend for increasing public involvement in research. One of the reasons for involving service users and carers in research is to add differing perspectives to the commissioning and design of studies which would normally have decisions made by clinical or academic professional researchers. It is also thought that public involvement can help to improve the focus of the research and achieve better outcomes through the provision of guidance as part of the design steering group, peer review of studies and bids, and by aiding decisions on dissemination and outcomes.

A recent evaluative study identified different indicators which might be applied when research involves the public in roles other than as research participants (Boote et al 2006). A Delphi study was carried out on principles and indicators of successful consumer involvement in NHS research. Consensus was reached on eight principles of successful consumer involvement in NHS research. There were few differences in how consumers, researchers and service user researchers rated the principles. Nolan et al (2007) show there is inconsistency in the way people who are not study participants are involved in research, in care decisions and in planning health care.

Background to the Study

All NHS Trust Chief Executive Officers hold responsibility for service user, carers and the public involvement in planning and prioritising health care needs and care delivery in localities. This role is normally delegated to staff with particular responsibilities to fulfil the policy requirements. At the time of this study, the structure for public contact with NHS Trusts was generally via the Patient Advice and Liaison Service (PALS) and the Patient and Public Involvement Forum (PPIF), managed by Community Health and Public Involvement Offices (CHIPI). This structure has since altered. Issues of involvement, advice and complaints are managed by Patient Advice and Liaison Services, and independent Local Involvement Networks (LInKs) which have been set up in each area. The management of this structure is the responsibility of the Department of Health and the Patient Safety Agency.

Research and Development offices in NHS Trusts have a responsibility under the Research Governance Framework for Health and Social Care (Department of Health 2005) to encourage service user and carer involvement in research. This may take the form of developing and sustaining service user involvement in

research as researchers planning and participating in studies, as reviewers of research or in dissemination of the results of research (Involve 2004). R&D offices also work with researchers to ensure they are able to meet the requirements of the NIHR for service user and carer participation in bids for research funding.

NHS R&D Offices in England and Wales maintain a database of research proposals and projects administered through their peer review and governance systems. This data offers an insight into the types and quality of research undertaken. Accurate records of the number of research proposals seen by each office do not exist. A national research register (NRR) was maintained until 2007, and NHS Trusts in receipt of Department of Health research support funding are required to submit an annual report detailing research activity, but these sources of information tend to be incomplete or record only those projects approved or with external funding. The proposals reviewed by Research Ethics Committees (REC) offices are reported as 7000 annually (<https://portal.nihr.ac.uk/Pages/NRRArchive.aspx>) and provide an indication of the numbers of projects being undertaken. However, they also have to be treated with some caution as not all project proposals require REC review and indeed some receive REC approval but are never undertaken, particularly own account.

Service user involvement forms part of the R&D Offices' interest but is not necessarily a key element of the work as their role is to ensure the service user and/or carer perspective has been taken into account in the research design. This study aimed to define the extent and the range of service user involvement in research as shown by protocols and projects reviewed by the R&D Offices in NHS Trusts in England. It was hoped that the data would provide a view on whether there had been a change in the type of research proposals submitted i.e. an increase in proposals that include service users' involvement in the studies since public involvement became a key driver for the NHS and health research. This would identify the current trends underlying the context of service user involvement in NHS research, and the range of service user and carer research activity in England and Wales through Research and Development and Governance Offices. The data would also provide information that could be used for comparison in further study.

The National Health Service Research and Development (NHS R&D) Forum is the network for those involved in planning and managing research in health and social care. It is supported by the Department of Health to provide advice and support for R&D offices which, amongst many other responsibilities, review research proposals submitted for ethics and NHS approval. R&D Offices fulfil a governance responsibility by facilitating the peer review of the studies submitted and subsequently providing regular audits. They also provide an opinion on the acceptability and quality of the research among the local populations. Changes in the organisation of R&D offices since the survey was conducted, (brought about by the introduction of the Department of Health strategy 'Best Research for Best Health' and the introduction of the NIHR and various Comprehensive Research Networks), have had a profound impact on the level and type and support for service user involvement. This study provides a view of the pattern of service user involvement in research, which is not otherwise reported, due to the context of data collection in R&D Offices.

The NHS R&D Forum has working groups of members who reflect aspects of the work of R&D Offices. One of these is the Service Users and Carers' Working Group (SUCWG). This group plans work annually that is of interest to NHS Trusts, social care, Universities, the Department of Health, and, primarily, service users

and carers and in the area of service user and carer involvement in research. An issue of interest to the SUCWG was whether there was any evidence of changes to NHS research trends in topic, resources, or other influence brought about by Department of Health policy and guidance advocating service user involvement and the impact of service user involvement. They also wanted to know about any change in direction to research proposals based on service users and carers being involved in studies. An examination of the literature and other research that had been conducted found no studies that answered these questions. The aims of this study therefore reflect this absence of information, and the patterns arising from the context of data collected for service user and carer involvement in research.

The Study

The aim of the study was:

- To examine the application of policy to the involvement of the public and service users and carers in the research process and the review of research.

The objectives were to:

- Identify the ways in which local user and carer participation occurs in NHS research
- Assess the impact of this participation
- Evaluate how service user and carer involvement is achieved
- Illuminate and disseminate good practice in this field
- Provide guidance for NHS R&D staff in service user and carer involvement

Methodology

Method

A survey method was selected as the most appropriate method of data collection due to the numbers of R&D offices across England and Wales and offered the potential to use either postal or electronic means of distributing the survey. The survey was developed by the SUCWG using a process of consultation and consensus amongst members. The survey was then reviewed by Involve¹ and senior managers from the RD Forum prior to being piloted on a small sample of R&D managers (≤ 5). Following a further review by the SUCWG, the survey was sent electronically to all R D offices in England and Wales by the administrators of the RD Forum in June 2006. In 2006 a total of 315 NHS R&D Offices were members of the NHS RD Forum in England and were therefore eligible to be included in the survey of service user and carer participation in research studies. It was anticipated that the survey would be completed by R&D managers or Research Governance leads in each office.

¹ INVOLVE is a national advisory group which promotes and supports active involvement in research in the NHS, public health and social care. It was established to promote public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used.

A second (reminder) request was sent out at end of September, again by email. Further requests were made personally by the Working Group members, some of whom are R&D Office managers. Completed surveys were returned to the RD Forum either electronically or hard copy. Hard copies of completed surveys were obtained by the administrator and given to the research team. These were anonymised so the research team were unaware of the identity of the R&D manager who had completed the survey.

Data analysis took place during May and discussion and editing of the final report, by the SUCWG members, occurred from December 2007-March 2008.

The Survey

The survey instrument was developed through the SUCWG, consultation with the NHS RD Forum management and INVOLVE. It comprised of 19 questions in three sections. The first section asked for numbers and types of research studies that were handled by the R&D office, the resources available to support service user involvement, and consultation with service users and carers by researchers submitting protocols. The second section asked questions about the specific activities and processes used by the R&D Office. The questions explored the links and contacts between the R&D Offices and service user groups locally. The third section asked about handling of applications that involved service users and carers, and any issues locally, resolved and unresolved, that were concerning researchers, or their offices. Finally, Research & Development managers were asked about their impressions of the impact of service user and carer involvement, in research, in their local area.

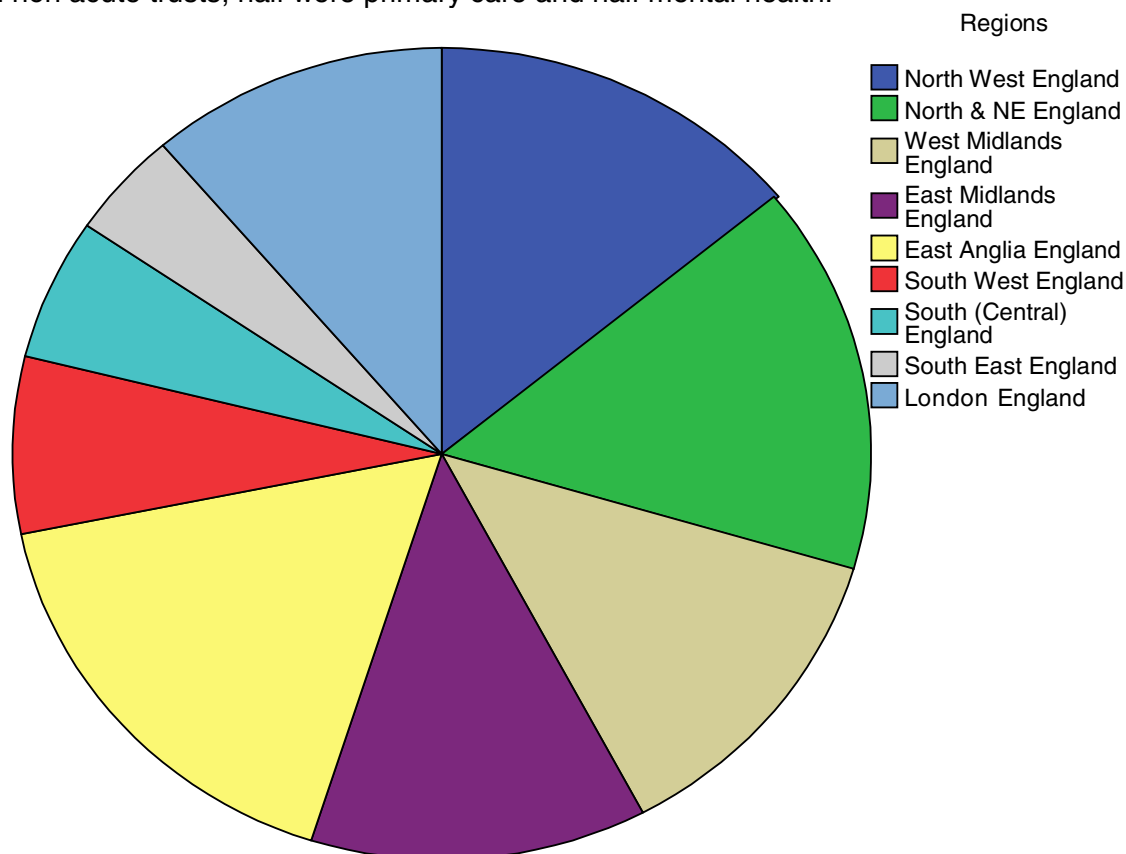
A definition of service user and carer involvement in research was included in the information accompanying the survey. The SUCWG felt that it was necessary to define involvement as, although Involve present a clear definition (see www.invo.org.uk), different definitions of involvement do exist within health services. Use of terminology between health professionals, researchers and service users may also exist. The research team were also clear that participatory and collaborative research referred to the involvement of service users, carers and the public at specific stages of the research process such as: identification of topics, prioritisation, commissioning, designing research, managing and undertaking research, analysing and interpreting results, disseminating or evaluating outcomes of research.

Analysis

Data was entered into a database and analysed using SPSS. Analysis included identification of the types and range of research studies that the R&D offices reviewed annually and the frequency of each type of research dealt with by the offices each year. The validity of the questionnaire is demonstrated by the mean, median and mode of the responses which have a significant relationship. Kruskal-Wallis test and Levene's test were used to analyse the results.

Results

The final response rate was 24% (n=71). The respondents were grouped into nine regions coterminous with the NHS England and Wales regions (Strategic or Specialist Health Authorities) at the time i.e. the North West, North East, Yorkshire and the Humber, West Midlands, East Anglia, South West, South, South East and London. Two thirds of respondents were from acute care trusts, and of the third from non acute trusts, half were primary care and half mental health.



From the responses, East Anglia reported the highest number of studies/project applications, followed by South West, North and North East England, and North West England, East and West Midlands. Respondents in the South East reported the lowest numbers of studies in progress, however the response rate was 24% and this may reflect the discrepancy. There was a wide variation in annual numbers of studies submitted to R&D offices (see Table 1), but this may not correspond to the level or type of funding received by each organisation as the size and scale of the project may vary considerably and high numbers may reflect a number of small scale projects or student research. Thirteen offices (18.3%) received less than 30 studies annually. A quarter (25.4% n=18) of R&D Offices received between 30-49 studies annually. Less than half the respondents (43.7%; n=31) received less than 50 studies annually, which means that most of the respondents, (56.3%; n=60) received more than 50% of the total annual submissions of studies. 23.9% (n=17) reported receiving more than 90 studies annually.

Table 1: Annual numbers of research study protocols received in each responding R&D Office in England

Numbers of research studies received annually per office in England (workload)	Each office workload as a % total in England
Less than 30 studies per year	18.3%
30-49 studies per year	25.4%
50-69 studies per year	18.3%
70-89 studies per year	14.1%
More than 90 per year	23.9%
Total	100.0%

Respondents were asked how many commercially sponsored studies were submitted annually for review (assumed to be trials), and of the non-commercial studies how many used qualitative and quantitative methodologies. Commercially sponsored studies form less than a third of the majority of the work of R&D Offices. 83.1% of respondents reported seeing less than 30% of these types of studies in relation to the total range of types of studies that are sent for approval. 81.7% reported that up to 50% of their work was in managing non-commercial qualitative studies and 69% in managing non-commercial quantitative studies.

The results indicate that most of the studies that R&D Offices review or manage are normally local Trust research studies (known as 'own account'), studies that relate to academic study awards, or funded health studies' research that does not have major commercial sponsorship or funding. This reflects differences in types of research and development. For example, acute trusts carrying out research in oncology, or cardiac care are more likely to be involved in clinical trials; mental health trusts are less likely to do so and may focus primarily on qualitative research.

R&D Responsibilities for Service User and Carer Involvement:

The survey asked whether the R&D office identified 'user and carer involvement' in any of its R&D staff role descriptions; what amount of time was allocated to the inclusion of service users and carers; how the office was planning to increase involvement by the public in its activities, and what contact the office had with local NHS service users and carers who are interested in health and social care research.

Respondents stated that the majority of roles (57.7%; n=41) in R&D Offices have some responsibility for service user and carer involvement in research. Some respondents detailed the types of roles, such as Head of Consortium, Research Fellows, R&D Manager, amongst others. However, the time or resources allocated to these roles varied. Nearly half (42.3%; n=30) had no time allocated, and three of these were R&D managers; nearly a third (28.2%; n=20) had half a day per week (0.1wte) and of these 17 were managers. Of the total (n=71), four posts had more than half a week allocated to service user and carer involvement in research (5.6%; n=5), and two of these (a manager and a researcher) were able to allocate four days per week (0.8wte). Several respondents were unable to specify exactly the time allocated and made an assessment of one day per week or 0.2wte across the staff group. Two thirds (70.4%; n=61)) of respondents said they had formal and informal contact with local service user and carer groups.

Contact and Communication Between the Service User and Carer Community and the R&D Office

The survey asked about specific processes for making and maintaining contact with service user and carer representatives and members of the public in NHS Trusts, and local areas, and with patient support groups for specific conditions. Information on best practice in facilitating representation of service users and carers is sparse. Information on how service users contact R&D Offices is equally difficult to find and appears to be unrecorded or unavailable. This survey asked how contact is made with service user and carer representatives, and how users and carers normally make contact with the R&D Office either as potential researchers or as members of the public who wish to be involved in participatory research. The survey also asked for information on where the work of the R&D Office was advertised to the public, and service user and carer groups.

Most of the R&D Offices reported knowing how to contact service users and carers in their Trust locality. Many stated they used the PPIF as a link to the service user community. There were a range of methods of making and maintaining links with service users and carers, with many R&D Offices having developed a type or variation of a Service User Research Forum or a User Advisory Group for Research. Others communicated by email, by letter, telephone, through existing user groups, the local media, web based groups of the local PCT, or the Trust Research Board. In one trust INVOLVE had a representative on the Trust Executive Board. Some reported they used the Trust Board of Governance for information, or formal links to service user groups. A small group of respondents reported that they had no way of contacting local service users.

Responses to the question of how the public contacted the R&D Office identified some common features of the routes of contact. Some respondents said that they contacted users 'directly'. Other offices reported that the public communicated with them by telephone, in writing, by email, or through the web sites of the Trusts. These web sites were where the Offices understood they 'advertised' their work and services. Some stated they advertised by posters, newsletters or flyers distributed through service user and carer groups, the PPIFs, or the user/carer partnership council. One response stated

we know that our information reaches the local public because we are often approached by patient groups wishing to carry out a survey for advice etc. These contacts are invaluable first steps to collaborative working.

The survey asked how the public were involved in the work of the R&D Office. 12.7% (N=9) reported that service users were in contact with the R&D office as researchers or potential researchers. 26.8% (n=19) reported that the public were in contact with R&D Offices as planners and reviewers. 19.8% (n=14) reported that contact with the public was through research governance review panels, and as reviewers for protocols (see Table 2).

Table 2: How the Public is Involved in R&D Office Work

How the Public is Involved in R&D Office Work	Type of Involvement	% of Total
In Research Governance review panel	Consultation	9.9%
As researchers	Collaboration or partnership	12.7%
As reviewers of protocols	Collaboration	9.9%
To set priorities or plan research programmes with researchers	Partnership	2.8%
As researchers and as reviewers	Collaboration	4.2%
As researchers and to prioritise or plan programmes	Collaboration	1.4%
As researchers, reviewers, planners	Collaboration or partnership	12.7%
In meetings of specific representatives	Consultation	1.4%
Other additional		4.2%
None		40.8%

Respondents to the survey were asked about positive or negative outcomes of involvement from those who had experience of public or service users and carers' involvement in research. On the whole, those who had strong links with service users and carer organisations and incorporated involvement in their activities reported 'overwhelming positive experiences' for R&D staff and for service users and carers and their group representatives. There were comments such as:

We find lay members' involvement very stimulating and worthwhile, adding value to projects, assessment and a better understanding of the user perspective'.

Others, whilst commenting on the positive nature of involvement, commented:

Needs a lot of time investing,

However, others reflected some of the barriers and difficulties faced:

We have struggled for many years to engage users and carers in R&D and have been met with many obstacles in our way. That is not to say we don't want users and carers in R&D.

The survey asked how the R&D Offices obtained resources to support public involvement. This was seen as a particularly important issue by the SUCWG as R&D offices were experiencing a reduction in funding due to the introduction of the new Department of Health Strategy for Research and Development 'Best Research for Best Health'. Although there was no dedicated element of Department of Health funding for this activity it was known that some R&D offices were supporting service user involvement from R&D funding and that there was likely to be an impact on their activity.

Table 3 identifies the level of resources available for service user and carer involvement in research, at a time when the concept of involvement is stated as a Government developmental priority. This table shows that the majority of respondents either had no dedicated resource to support public involvement or were utilising other research funding. Few had been successful in acquiring

funding to support this activity. The responses indicated that in 73.3% (n=52) of trusts either no time was made formally available, or half a day per week (0.1 wte) supported service user and carer involvement in research.

Table 3: The Support Provided for Service User and Carer Involvement in Research and Development

Method of Support for Public Involvement	% of Total Respondents
Funds are set aside from R&D budget (may be support funding)	12.7%
Responsive funds	14.1%
Allocation from external source (may be DoH for example)	15.5%
Competitive resources	1.4%
Central research funding (likely to be DoH support funding)	7.0%
No resources identified	49.3%

Respondents were also asked what funding was required for service user involvement in research. The resources allocated also varied and were often described as ‘benefit in kind’ or ‘travel expenses’ or ‘remuneration for out of pocket expenses’.

If service users and carers are to participate effectively in research or research related activity, training is vital. An earlier survey by the SUCWG (unpublished) identified that there are many in-service training sessions, workshops, or courses available for both researchers and service users, to support the role of the public in participatory research. The range and type and level (academic difficulty and complexity) of these courses and sessions differ widely and include in house training, courses offered by the Research Development Support Units and the UKCRN, and University training. INVOLVE and other organisations have reported on these in the past (INVOLVE 2004).

The Trends in Public Involvement in Research (R&D Office Responsibility) since 2001

Since 2001, R&D applications that pass through R&D offices have to record whether the researchers have included or involved service users or carers or both in their planning of research studies. The survey asked a series of questions focused on how the impact of public involvement has made a difference to the workload, the ways of working and the needs of R&D Offices since 2001. A cumulative 57.8% increase seen in identifiable service user and carer involvement in applications increase was noted (See Table 4).

Table 4: Trends Noted By R&D Offices in the Type of Involvement in Research by Service Users and Carers Since 2001

Trends in the Type of Involvement of Service Users and Carers in Research Since 2001 (the previous five years)	100% (n = 71) of responses
Increase in numbers of applications with identifiable public involvement	46.5% (n=33)
No increase in applications with identifiable public involvement	39.4% (n=28)
Increase in applications with public/service user researcher lead (as Chief Investigator)	11.3% (n=8)
No increase in applications with public/service user researcher lead (as Chief Investigator)	1.4% (n=1)

Funding to support public involvement in research was another area of concern for the SUCWG. The study identified various forms of support but almost half (35) R&D offices reported having no resources for public involvement (see Table 5). Eleven offices reported having external funding, 10 having obtained responsive funds and 9 having funds set aside from budgets.

Table 5: Comparing the Method of Organisational Support for Public Involvement in Research

Regions	Funds aside from Budgets	Responsive Funds	Allocation External Sources	Competitive Resources	Central	No Resources
North West	2	0	1	0	0	7
North East	2	2	1	0	0	6
West Midlands	0	1	1	0	0	7
East Midlands	1	2	2	0	2	2
East Anglia	4	3	2	0	2	1
South West	0	1	2	0	0	2
South (Central)	0	0	0	0	1	3
South East	0	0	0	1	0	2
London	0	1	2	0	0	5
Total	9	10	11	1	5	35

Data were compared to understand how the public is involved in R&D office work, and to define the relationship this has with the resources (time) allocated to service user involvement in the roles of R&D officers. Table 6 provides one of the more important results that link resources to outcomes of involvement. Although the findings do not indicate how these results are justified, there is a distinct inverse correlation between resources allocated and outcomes of involvement of the public in research.

Table 6 Outcomes of Involvement Compared to Time as a Resource Allocated to R&D Roles for Service User and Carer Involvement in Research

Time allocated posts	In res. panel	As r'search's	As review's protocols	Set priorities progs. with research's	As r'search's & reviewers	As r'search's reviewers planners	In meetings of reps	Other additional	None
.00	4	2	1	1	2	1	1	0	19
0.1 wte	2	3	3	0	0	0	0	2	10
0.2 wte	0	2	1	1	1	0	6	0	0
0.4 wte	1	1	2	0	0	0	0	0	0
0.5 wte	0	0	0	0	0	0	1	1	0
0.8 wte	0	1	0	0	0	0	1	0	0
Total	7	9	7	2	3	1	9	3	29

Table 7 shows results for the different types of studies that R&D offices administer, linked to the time that is allocated to post for the work of service user involvement. The results of this independent test indicate that in relation to the total number of studies administered by the offices, more of the studies are non-commercial and use qualitative methodologies. The table indicates that less actual time and resource is allocated for service user involvement in those offices where more impact of service user influence is realised and non-commercial types of research studies use qualitative methods. However, the indications are that R&D offices are still investing significant elements of uncosted and unrecorded time and resource in this activity despite the lack of actual, i.e. designated and recorded, resources and support.

Table 7 The Relationship between the Types of Research Administered by R&D Offices and the Time Allocated for Service User Involvement

Equal variances assumed	F	Significance
Annual study numbers per office	3.381	.070
Type: commercially sponsored	.141	.708
Type: non-commercial qualitative study method	8.251	.005
Type: non-commercial quantitative study method	1.653	.203
Time allocated to post/s for user care involvement development and or management	.234	.630

Discussion

2006, when this study was conducted, was a significant point in the development of R&D in the NHS. At the time of the study, a significant number of the studies reported were 'own account' studies. Many of these were small scale local studies often led from within trusts by their own staff that lent themselves to service user engagement. It is worth noting that changes to Department of Health funding for research from 2006-07 have reduced the amount of 'own account' and 'unfunded' research (i.e. full economic costings were not applied but the studies were resourced from NHS trusts) and encouraged more large scale fully funded studies. A reduction of smaller scale studies may have had an impact on some levels of service user involvement e.g. collaboration in NHS lead research or user lead studies, but conversely may have increased involvement in the bid writing process and review of proposals submitted as part of bids for funding from the NIHR or funding councils.

Health and social care research policy and guidance has increasingly influenced the range, type and depth of involvement of service users and carers in planning, steering, participating in and disseminating research over the last decade. Work already published examines the involvement of service users and carers in research (Nolan et al 2007; Beresford 2005; Bernard 2000; Grant et al 2006) and the impact on research and the team from the process (Nicholson; Burr 2005; Boote et al 2006). Other studies explore the ways in which outcomes of service user involvement in research have been evaluated (Grant et al 2006; Bernard

2000; Cooke 2005) and the impact that service user involvement has on research studies (Rose 2003; Telford et al 2004, Minogue et al 2005) and outcomes (SCIE 2007).

This study asked local administrators of R&D in NHS trusts and local authorities about their experiences of these trends, and the effect the change in user involvement in research has had on their processes. The survey questions related to the experiences of R&D offices and the implementation of the requirement to involve service users and carers in the research process. Some of the difficulties in changing the perceptions of researchers were clear as comments indicated that a considerable amount of research that comes to R&D Offices has gone beyond protocol/ethics approval stage. This makes it difficult to ask researchers to revise their design if user involvement is unclear or not mentioned. The earlier stages of research design and planning are the most productive in terms of involvement and this is reflected in the requirement to include service users and carers in applications for NIHR funding. An overview of the current literature (1995-2008) around service user and carer, patient and public, involvement in research indicates that there may be some seventeen categories with which to understand this involvement at greater depth (Boote 2009).

Identifying the difficulties and barriers in the systems for involvement is crucial in facilitating successful involvement. This survey identified problems connected to communication, in order to identify the needs and concerns of service users and representativeness of the public. Administrative support was also an issue and seen as important in recruiting the public and keeping track of this through a database of the availability of service users and carers. This becomes important in specific groups of representatives, who may have received or whose relative received palliative care and died, or be in an active phase of a chronic illness, or in other groups whose meaningful participation has passed e.g. the condition has resolved or the representative no longer wishes to be recognised as a member of that group. It is interesting to note that one R&D office recorded the problems of representatives facing their physician as a service user. This has been reported in other research (Cooke 2004).

This incremental change to research and therefore researchers, and the research systems in health and social care, has had an impact in a range of ways. Respondents reported seeing changes in trends of the topic of research (priorities), the research question posed, and the research method (the process of answering the question). The increase in user lead projects has also lead to changes in the way the R&D Office understands and assesses risk in research studies, and its expectation of outcomes and the manner in which the results and findings are disseminated by service users and carers who have conducted the studies.

Risk is calculated in various ways, mostly in relation to the Trust and its business, but rarely from the service user and carer perspective. Most of the responses indicated that the risk to the trust posed by public and service user and carer participatory research would be calculated as any other risk. However, comments were also made that indicated a perception of increased risk with service user participatory research where the risk was perceived to be specifically to the public who participate, and to the reputation of the Trust in general. Research Ethics panels who review the ethical issues associated with studies in health services and care also hold this view. It can be said, then, that health services Trusts assume the trust of their local population, but have no trust in them. Comments by R&D offices that responded included the need for service users and carers to:

operate in a safe and secure environment

or that:

it is difficult to trust a lead researcher who has no track record of research or publications (but a great deal of enthusiasm) in comparison to a professional researcher.

Many comments suggested that extra advice and support was, would or should be provided under these circumstances. It is this feature of the R&D service that requires funding, resources and demonstrable input from training. The study then compared support in regions to support for public involvement. The range of difference in support and resources can be seen clearly in Table 5. Most funding is from external sources, and in two regions, few resources are available. Most offices report no resources at all.

In comparing the numbers of studies seen annually by R&D Offices with how the members of the public are involved in the R&D office work, the results indicate that if service users are involved in research it is likely that they are listed as researchers, or involved as planners, reviewers and researchers. Indeed, there is no record of the research qualifications of researchers, who are involved in projects as service users. This may indicate that if involvement is active (collaborative or in partnership) it is influential. Unfortunately, other study protocols convey 'participation' in the research is by 'subjects' rather than objective participants. As research topics have changed in response to service user involvement, so there has been a small change in the ways in which questions have been posed. The control over the research largely remains in the hands of professional researchers, rather than service users and carers, and this is reflected in the general lack of change in research methodology, so that traditional methods of the research process and ways of answering questions continue to be used. Although, there may be some notable changes to this in specific areas such as mental health research.

Conclusions

User participation in research is still in its relative infancy with many practical, ethical, moral, methodological and philosophical questions being debated. There appear to be issues of resources and funding for R&D Offices in their responsibilities for supporting service user involvement. These priorities compete with many other external to research and development, and service evaluation. The consequences of these decisions are that policies are rarely evaluated or implementation audited to convey rationale for further development.

The findings of this study indicate that there is an inverse correlation in the resources allocated to service user involvement in research, and the outcomes of involvement (Tables 2 & 3). This finding in particular supports the notion that service user involvement is patchy, inconsistent and reliant upon local 'champions' working in R&D Offices. NHS health policy has a reputation in its current form, for identifying need for change from the 'top' of the organisation at the Department of Health level. Policies are then filtered down the hierarchy, often re-interpreted on the journey, and arrive at 'the sharp end' of health service delivery or research project management in a form that is difficult to implement. This survey may have answered several questions regarding the variations in service user involvement in health service research. However, other questions remain that centre on the

incentives for (and consequentially resources for) and abilities of researchers to involve service users, patients and the public in research. The reliance of the Government and The Patient Safety Agency on local 'champions' to implement a policy on few resources lacks credibility and results in the identified inconsistency which causes difficulties of comparison.

The Chief Executive Officers of NHS Trusts are bound by their contract to involve service users and patients in the improvement of services and research into health services. Protocols funded by NHS and non-NHS resources require service user involvement, but do not demand a demonstrable quality of involvement. Ethics forms ask specific questions about service user involvement in the study preparation yet again avoid the opportunity to request the credentials of that involvement.

The imperative to involve service users and carers exists, but requires adequate support to ensure that they, and NHS researchers, are sufficiently trained and equipped to participate. This survey has therefore highlighted the way in which a policy of service user involvement in health services research, commendable in its aims and objectives, has been diverted and dissipated in its implementation by the external agendas of health services delivery and management priorities.

References

Beresford, P. 2005 Theory and Practice of User Involvement in Research: Making the Connection with Public Policy and Practice, in L Lowes and I Hulatt (eds) *Involving Service Users in Health and Social Care Research*. (pp 6-17) London: Routledge.

Bernard, W.T. 2000 Participatory Research as Emancipatory Method: Challenges and Opportunities, in D Burton (ed.) *Research Training for Social Scientists*. London: Sage.

Boote, J. 2009. *Patient and Public Involvement in Health and Social Care Research; a bibliography*. NIHR Yorkshire and the Humber, White Rose University Consortium

Boote, J., Barber, R., & Cooper C. 2006 Principles and indicators of successful consumer involvement in NHS research: results of a Delphi study and subgroup analysis. *Health Policy* 75 (3): 280-297.

Cooke, M. 2004. *An Examination of the Relationship Between Changes in NHS policy (1997-2000) and Three Patient Groups. An Empirical and Theoretical Study*. Unpublished PhD thesis: British Library of Political and Economic Science. London: The London School of Economic and Political Science.

Department of Health. 2001. *The Expert Patient: A New approach to Chronic Disease Management for the Twenty-First Century* London: The Stationery Office.

Department of Health. 1998. *In the Public Interest: Developing a Strategy for Public Participation in the NHS*.

Department of Health. 1999. *Patient and Public Involvement in the New NHS*. London. HMSO.

Department of Health. 2001a. *Involving Patients and the Public in Healthcare*. London. HMSO.

Department of Health. 2001b. *Health and Social Care Act: Section 11*. London. HMSO.

Department of Health. 2004a. *NHS Improvement Plan*. London. HMSO.

Department of Health. 2004b. *Patient and Public Involvement in Health: The Evidence for Policy Implementation. A Summary of the Results of the Health in Partnership Research Programme*. London. HMSO.

Department of Health. 2005. *Creating a Patient Led NHS*. London. HMSO.

Grant, G., Courtney, D., King, S., Minogue, V., & Walsh M. 2006. Accounting for Research: The Difficulties Posed for User-Centred Research, *Mental Health and Learning Disabilities Research and Practice* 3: 1: 5-19.

Involve, 2004 *Involving the Public in NHS, Public Health and Social Care Research: briefing notes for researchers*. Eastleigh: INVOLVE.

Minogue, V., Boness, J., Brown, A., Girdlestone, J. 2005. The Impact of Service User Involvement in Research. *International Journal of Quality Assurance* 18, No 2 & 3. Emerald.

Nicholson, P. & Burr, J. 2005 *Conclusions: Taking a Critical Perspective: Research Methods and the Role of 'Users' or 'Consumers'*, in J Burr and P Nicholson (eds.) *Researching Health Care Consumers: critical approaches*. Basingstoke: Palgrave Macmillan.

Nolan, M., Hanson, E., Grant, G., & Keady, J. [Eds]. 2007. *User Participation in Health and Social Care Research: voices, values and evaluation*. Open University Press/McGraw-Hill; Maidenhead, Berkshire.

Involve: 2004. *Involving the Public in NHS, Public Health and Social Care Research: Briefing Notes for Researchers*. West Sussex: Involve DH.

Rose, A. 2003. Having a Diagnosis is a Qualification for the Job. *British Medical Journal*, 326, 1331.

Social Care Institute for Excellence. June 2007. *Participation: finding out what Difference it Makes*. Social Care Institute for Excellence.

Telford, R., Boote, J., Cooper, & C.L. 2004. What Does it Mean to Involve Consumers Successfully in NHS Research? A consensus study. *Health Expectations* 7: 1 – 12.