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CENTRE FOR HEALTH ECONOMICS

A Database of Examples of Consumer Involvement in Research

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PREFACE

This report and the accompanying database was commissioned by the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme at the start of 1998. The main aim was to develop a resource that would indicate the state of consumer involvement in medical and health service research. The report summarises the material on the database and describes how it was collected. The database, which will run on any personal computer with Windows 3.1 or later, gives details of more than 400 projects involving health service consumers in research. Users of the database may be interested in two other projects, commissioned at the same time as this work. One, conducted by the University of Warwick, developed a database of research involving black and ethnic minority consumers. The other, conducted by a team from PREST at the University of Manchester, compared lay and professional perceptions of the medical research agenda. Appendix B gives details of how to get more information on these projects.

INTRODUCTION

This report describes the construction of a database of examples of consumer involvement in research. It summarises the material on the accompanying database and discusses some of the problems of finding and classifying suitable examples.

The database was commissioned to:

map the field of consumer involvement in research, by recording both current and recent initiatives, and the individuals and groups carrying out the work;

provide material for the Standing Advisory Group on the issues raised by practical examples of consumer involvement in research;

provide examples of work that might be helpful in suggesting ways of involving consumers in research.

Our brief was to concentrate mainly on examples of consumer involvement in research and especially on work that would not easily be located in other databases such as MEDLINE. However, beyond that it is difficult to circumscribe exactly what has been included and what has been left out - although the discussion of criteria below presents some guidelines (see section 4.2). However, we can say what this database is NOT intended to be.

Thus, it should be emphasised that, whilst a few bibliographic references and reports have been included, this database is NOT a database of academic (or even lay/popular) articles about consumer involvement in research or even about the issues raised about involving consumers in research.¹ Some of these articles are very interesting and contribute to our understanding, but it was seen as important to provide primary material in order to deepen our understanding of this area. Moreover, the usual route to identifying appropriate materials - via a keyword/key phrase search of bibliographic databases - is not easy because it generates either too few or too many articles. In part this is because many of the more radical examples of primary research work with consumer involvement, that are successful within their own paradigm, would not meet the conventional >scientific= criteria of health services research and would therefore not be included in classical academic databases (see discussion below); but in part it is because the current classification criteria are inappropriate. Indeed we would hope to provide some insight into the ways in which this kind of material could be classified in order to facilitate future searchers.

Equally, although our route to collecting information has, mostly, been through organisations and we have encouraged groups and organisations to submit entries about themselves, this is NOT a database of consumer groups active in health or self-help organisations. There are very well established databases of consumer organisations - such as HELPBOX etc. - and we would not wish to duplicate those. However we would claim that we have provided a database which is the subset of those

¹ The PREST project report (see Appendix B) has systematically covered this literature.

organisations which are involved in research with an element of consumer involvement at the time of data collection, from March to November 1998.

We should also stress that the material on the database has not been selected as examples of especially good or outstanding practice. We have included most of the material we were sent, excluding a very few items where we were unable to detect any form of consumer involvement other than patients being subjects in trials. Our brief was to be as inclusive as possible, to collect together a set of materials that would help others decide what is good or bad practice. Users of the database should bear this in mind and not assume that everything they see is worth replicating.

2. DESIGNING THE DATABASE

2.1 The range of information to record

Several types of information are needed to support the different aims of the database:

1. contact details for organisations and key individuals carrying out research involving consumers
2. general details, such as the aims and methods, of current or recent research involving consumers
3. more specialised details on the type and level of consumer involvement.

Figure 1 - Data items in database

Code numbers to identify the principal organisation and the project
The project title
The aims - including details of the setting for the work
The type and extent of consumer involvement - (free text and coded fields added by the project team)
Whether black and ethnic minority groups were involved
Project start and end dates or other relevant information on duration
The funding source and type
Main features of design/research methods
Details of publications/reports
Project team code for the type of database entry
Name of the originating organisation
Project team code for the type of originating organisation
Contact name, address, phone and fax

Because of the emphasis on projects and contacts, the material collected and the organisation of the database departs from that of a typical bibliographic database. The information kept on each entry is summarised in Figure 1. This list of items was chosen for compatibility with the National Research Register (NRR) as early discussions with the funders suggested it might be distributed as part of the NRR package.

The headings on the data collection form (see Appendix A) are very similar to the above list. Users of the database will note that information on each entry may be incomplete, especially when information has been derived from sources other than the forms.

Keyworded fields have been added to the entries to enable us to compile the summary tables for this report and to provide some consistency of terminology for database users. However, the project was neither funded nor equipped to undertake more extensive keywording - for example, to translate topic areas and design features into Mesh terms. Indeed, the proposed software was chosen because by indexing every word in the database it obviates much of the need for keywording.

2.2 Software and distribution

The aim of the project was to create a package that is both simple to use and easy/cheap to distribute. Because the project did not budget for significant programming effort, this would have to be achieved using proprietary software without the benefit of customised user interfaces.

Blackwell=s Idealist most closely approximates these needs. It is an unusual package in several respects - as it can combine records of different types in the same database and is specifically intended for free-text searching. Some of its most relevant features for our purpose are: that all text fields are fully indexed; that it is menu driven; and that it provides a small read-only module so that copies of the database can be distributed without the need for users to have their own software.

3. COLLECTING MATERIAL FOR THE DATABASE

Most of the material for the project has been obtained from postal surveys of organisations likely to conduct or commission research with an element of consumer involvement. A typical version of the data collection form and covering letter are included as Appendix A. Material has also been found from research archives, other research databases and bibliographic databases. The main types of sources used are described below.

3.1 Health charities and support groups

Health charities and support groups have been an important source of material because of their efforts to influence the research agenda and, where resources permit, commission their own research. Many of these groups were approached with personalised requests for information. They were identified from sources including the Help for Health Helpbox and a complete list of medical charities from the charity commission web site. The mailing concentrated on those that mentioned Aresearch@ in either their title or statement of aims.

3.2 Conference attenders and presenters

The January 1998 Consumer Involvement Conference >Research - What=s In It for Me?= (Department of Health, 1998) provided a unique opportunity to identify and approach researchers with an active interest in consumer involvement. The project

circulated requests for information with the conference packs and staffed a display where enquirers were asked to supply details of relevant work. Subsequently personalised mailings were sent to all conference attenders and presenters.

Reports from other conferences such as the Patient Partnership event in May 1997 (NHS Executive - 1997) have also been a rich source of contacts and database entries.

3.3 Community Health Councils

Much of the research carried-out by CHCs is potentially eligible for inclusion on the database as it is often inspired by lay views and carried out by volunteers. The Association of Community Health Councils for England and Wales (ACHCEW) keeps a central database of CHC research and copies of many of the project reports. For the past three years this database has included short project descriptions. Members of the project team read each of the 400 entries for this period and identified approximately 80 projects to follow-up. (Earlier projects have been ignored because it is impossible to judge their relevance from the title alone.) Reports of these projects were read at ACHCEW and database entries were completed for just over 50 of them. Deciding which CHC projects to include raises a number of key questions regarding the nature of consumer involvement. These are discussed in section 4.5.

3.4 NHS R&D coordinators

Details of current and recent NHS R&D work were obtained from the National Research Register and the database should include all pieces of NHS funded research on the NRR with some consumer involvement. The project has also approached R&D coordinators for details of other work in their trusts, health authorities and universities. They were sent database forms to complete personally or for forwarding to people who are involved in relevant work. We sent-out personalised requests for assistance to coordinators based on names from the Regional Office mailing lists. R&D coordinators in Wales have been similarly approached.

3.5 Following-up leads from the EPI project

It was important for the project to build on the previous work that The Centre for the Evaluation of Health Promotion and Social Interventions (EPI) undertook for the Standing Advisory Group on Consumer Involvement. This has been achieved in several ways. Firstly by entering details of the organisations they contacted onto our main database; and attaching a summary of these organisation's activities as described in the EPI report (Oliver and Buchanon, 1997(1)) and bibliography (Oliver and Buchanon, 1997(2)). Secondly, by following-up the works cited in the bibliography and by re-approaching those organisations mentioned in the EPI report for which there were insufficient details to complete a database entry.

3.6 Phone follow-ups to postal surveys

We have contacted more than 200 organisations and individuals by phone to follow-up postal requests for information. As these follow-ups are very resource intensive we have only targeted those people likely to be most active in the field, such as the presenters

and selected attenders from the January 1998 Consumer Involvement Conference. The phoned follow-ups have proved very effective.

3.7 Bibliographic searches

Several pilot searches of major bibliographic data bases have been attempted, but there are major difficulties identifying key terms or phrases that will pinpoint relevant material: the criteria relating to consumer involvement were clearly not uppermost in the minds of the compilers of these large databases. There are two further difficulties in seeking information via this route. Firstly, that examples of consumer involvement tend to be described in reports and other grey literature that do not get included in major medical and health research databases; secondly, that the conventional formats for writing research articles do not invite descriptions of consumer involvement - even when this has taken place.

As an alternative approach, and to follow-up the references cited in Oliver and Buchanon, 1997(2), we have arranged for a research assistant to visit relevant London libraries, including those at the King=s Fund and The College of Health. She has asked local information staff for their help finding suitable items and has looked for material known to be relevant and for publications of organisations in the field. The purpose of this exercise is to try to establish whether there is any pattern in the way this material is classified or shelved. This has proved a frustrating exercise as the possibility that research might include consumer involvement did not seem to be taken account of when classifying and cataloguing material. It underlined the need for the issues surrounding consumer involvement to be better publicised to people involved in the classification and acquisition of research publications.

3.8 The current state of the database

A version of the database containing more than 430 entries can be found on the two discs at the end of this document. However, the discussion and tables in this report refer to a slightly earlier version with 404 entries. The entries on the current version have been checked with more than 90% of contributors. However, we apologise if there are people who have not been contacted, or suggested amendments that have not been implemented. Further versions may be released on disc, but the main aim is to mount and maintain the base on a Web site with the possibility of rapid correction and updating. This is likely to be the responsibility of the Help for Health Trust who are hoping to have Internet access arranged sometime in 1999.

4. DEVELOPING THE DATABASE

4.1 What is consumer involvement?

The first problem in developing the database was to define what is meant by consumer involvement and hence what should or should not be included. There is a >theoretical= problem in deciding on what counts as consumer involvement in research. For example, at one extreme there are many research projects that only collect consumer feedback using structured questionnaires, but could be included because they have previously involved some research subjects in focused group discussions as a pilot or

preliminary to the main survey. In contrast, patient support groups which themselves carry out research do, in a sense, involve patients not only at all stages of the research process, but the group itself has decided on the topic and designed the approach to the research. The issue is therefore not only the *stage* at which consumers/patients are involved in the research process, but also the *nature* of their involvement.

A second dimension is who actually counts as the consumer (see Carr-Hill et al 1989). For example, at the extremes of the age ranges: where the patient is a child, the relevant consumer is usually the parent; and where the patient is elderly and infirm, the relevant consumer is probably the daughter or son. These surrogates will nearly always intervene even if only at the level of interpretation.

A third dimension is what counts as >consumption=. Many of those involved in alternative therapies see themselves as producing as well as - or instead of - consuming health; and would therefore define the research process differently.

We had thought that, in the technical context of developing a database, we could avoid the controversies and discussions about consumer/lay person/patient and over what was meant by consumer involvement simply by working *ostensively*; that is by building up a definition of consumer involvement from detailed accounts of the nature and type of involvement. Indeed, in our initial tender we argued that we could specify the agencies that are likely to be involved in promoting consumer involvement - such as CHCs and steering groups in patient involvement initiatives who both generate and catalogue much of the grey material in this area - and thence build up a definition of consumer involvement.

This optimism for a quiet life has, however been shaken by our experience both at the Conference, in our discussions with the Project Steering Group, and by reading through the several hundred replies to our trawls for information. No one model emerged from these sources, instead we encountered radically different strategies for involving consumers in similar types of research. Therefore we have had to take a series of decisions about what should be included in the database (the criteria for inclusion) and how to recognise and classify the different types and nature of involvement.

4.2 Which classes of material to include?

The first set of criteria were needed to ensure that the database contained material to support the aims described in Section 2.1.

Four types of material seemed to meet these requirements. The first two, research projects with consumer involvement and individuals/organisations active in consumer involvement have already been described. The third comprises activities that involve consumers less in the design and execution of research than in disseminating and implementing research findings. Such activities can range from the production of guidebooks, consumer leaflets and interactive information systems, to projects in which consumers have a role in ensuring that service developments are evidence-based. A fourth group of entries refers to initiatives to involve consumers in service priority setting rather than research. Not all these exercises could be described as research, but they

may use methods of public consultation which could be transferable to research; hence their inclusion.

Because several of these headings cover a wide range of material, the four basic groups have been expanded to nine for the purpose of classifying the entries. These nine groupings are listed in Table 1. This Table also shows that a majority (two-thirds) of projects are either research projects or research programmes - an unsurprising result since much of the data collection was directed at this type of material.

Table 1: Types of Database Entry.

Type of Database Entry	Code in database	N of each type	% of entries
An empirical research project with consumer involvement	1	246	60.9
A research programme with consumer involvement	2	17	4.2
An initiative to lobby/inform research agendas	3	5	1.2
An entry describing an organisation (or individual) active in consumer involvement (not a project or specific initiative)	4	30	7.4
An initiative to disseminate results of a single piece of research, knowledge of a medical condition, or issues in health care; and work that involves consumers in ensuring that results of research are adopted in practice.	5	32	7.9
Items describing research into (and reviews of) consumer involvement	6	11	2.7
Reports of initiatives to involve people in health care and other local service planning: using methods that may be transferable to involving consumers in research.	7	49	12.1
Systematic reviews involving consumers.	8	3	0.7
Development of measuring instruments - especially user informed outcomes measures	9	11	2.7
All types		404	100.0

4.3 Classifying types of consumer involvement

Having decided on the basic types of material to include, we began to develop a set of headings to describe each of the different forms of consumer involvement in research. We took as our starting point the stages in the classical model of research: hypothesis

formation (or question identification), proposal writing, submission to funders and approval/modification, design of research protocol in detail, day-to-day management of the research etc.. Based on this model, we tried to produce a classification in terms of the (potential) consumer involvement at different stages of research (suggesting topics, commissioning, designing, managing, data collection, analysis and interpretation, dissemination). These are categories 2-7 in the attached classification scheme (Table 2). However, although we found that was a useful exercise, this theoretical/textbook model of the components of research did not appear to capture the nature or style of involvement in a significant minority of the entries.

There seem to be a number of reasons for this mismatch, of which the following may be the most important. Firstly, that the original classification (groups 2-7) omitted a general consumer orientation in research: for example, a concern with incorporating, at least theoretically, consumers views through a pilot or initial focus groups; or a concern with the ethical issues involved with humans as subjects of research; or general discussions about consumer/lay involvement. Three new categories 11, 12, 13 were created to cover these topics.

Secondly, that the original classification did not take account of the increasing tendency for consumers to be organised into groups which may themselves undertake research or seek to be partners in research carried out by medical and academic professionals. The classical categories are appropriate to the cooption/involvement of consumers in professionally inspired and managed research; and they may even be appropriate to describing involvement in projects that are effective partnerships between consumer groups and professional (though more on this later); but there are clearly roles that consumer groups play in relation to research that are not fully described by the categories derived from the classical paradigm. Such roles include more general attempts to stimulate consumer involvement by lobbying to influence the research agenda (category 1) and popularising and promoting the implementation of the results of research that had been written up elsewhere. These last two are covered by the new categories 8-10.

These two new categories develop but do not challenge the classical model. As such, they may not be appropriate for describing some of the more radical projects we encountered. Although we came across work which questioned rather than extended the classification we felt that it was beyond the brief of the project to develop a completely different set of categories to describe these activities. We can only apologise to anyone who feels that our descriptors do not do justice to their approach.

Categories based on processes outside the classical model of research are needed not only for the more radical or proactive approaches. There are a set of activities which support traditional research, but which cannot be described in terms of the stages of the research model. For example, some groups feel they can best help by fund raising or by encouraging their members to be research subjects rather than trying to influence the conduct of research. These types of activity are represented by two more categories: fund raising for professional research (15) and recruiting subjects for research(16).

The complete scheme contains one further category (14); added to describe involvement in service planning rather than research. Such work is included on the

database when it uses methods that may be adapted to involving consumers in research.

All the categories and their associated key terms are listed in Table 2. Each project in the database has been classified using this scheme and many of the projects were found to include more than one type of involvement. We identified 886 examples of involvement in the 404 projects and Table 3 summarises the frequency with which each type occurred. The most common types of involvement are where consumers are the subjects of research, but have some opportunity to control and direct the information they supply; and where consumers are being consulted on the monitoring and audit of service delivery. Together these account for 40.7% of all examples of involvement.

Table 2: Types of consumer involvement

	Type/area of consumer involvement	Key in database
1	Influencing research agendas and lobbying	INFL_AGENDAS
2	Suggesting/choosing topics for research	SUGGEST_RES_TOPICS
3	Commissioning and funding; and reviewing proposals	COMMISS_FUNDING
4	Management and design of research	MANAG_DESIGN
5	Data collection	DATA_COLLECTION
6	As proactive subjects of the study; with some control in the process of supplying information.	SUBJECTS
7	Analysing and interpreting results	ANALYSIS_INTERP
8	Reviewing a study or body of work	REVIEWING
9	Disseminating results of a study or group of work; involvement in schemes to provide information to consumers such as producing guidebooks/leaflets for patients and various schemes to empower patients through information provision.	DISSEMINATION
10	Implementing the findings of a study or body of work	IMPLEMENTATION
11	Reviewing or discussing issues in /examples of consumer involvement (e.g. this project) Includes evaluating/auditing examples of consumer involvement	STUDY_INVESTIGATION
12	Work which assess from a consumer standpoint the ethical issues associated with research and the mechanisms by which consumer interests can be safeguarded: for example, discussions of the ways in which ethical committees can be encouraged to be more sensitive to the needs and feelings of consumers.	ETHICS
13	Work which allows/encourages consumers to play a role in monitoring or auditing existing health and other care services. Needs to be more than a basic survey of consumer views to count as an example of consumer involvement. Examples of good practice in this category may suggest ways of involving consumers in research.	AUDIT_MONITORING
14	Work which allows/encourages consumers to play a role in setting priorities for health services and to become involved in service development: at a minimum involves the collection of consumer views on priorities and service development. Needs assessment exercises with implications for care planning are included under this heading.	PRIORITY_SETTING
15	Fund raising for professional research	FUND_RAISING
16	Recruiting subjects for research (typically from the membership of a consumer support group)	RECRUITING

Classifying involvement in this way naturally leads to two further questions: how much of each type of involvement is required before a project is included on the database; and how can we be sure that this is really involvement by consumers, rather than, say, professionals acting as their proxies? Both questions are given added urgency by the increasing professionalisation of consumer groups and the tendency for some groups to represent very broad constituencies.

4.4 Deciding whether there is sufficient involvement to include a project in the database

The classification in Table 2 was a convenient checklist when examining projects for aspects of involvement. It was mainly used for selection when we had access to databases of potentially eligible work, such as the NACHCEW archive and the NRR. Here we were not just looking for work with some basic trace of involvement, but wanted to find initiatives that were in some sense distinctive because of their consumer involvement. Consequently we looked for projects with features such as the following:

- it looks at topics suggested by consumers that other research ignores
- it is more ethical in its treatment of its >subjects=
- it is less hierarchical
- its designs are more flexible and can evolve to match the phenomena
- it is not rigidly committed to a single research hypothesis
- it collects greater detail
- it takes advantage of shared experience between data collectors and subjects to get truer accounts
- it evaluates itself and other research in terms of the needs of consumers not the academic/medical research community
- it presents its results in ways which are geared to consumer needs.

No single work is likely to have all these characteristics, but any attempt to do any one of these would qualify a work for inclusion on the database.

4.5 Measuring levels of consumer involvement

The need to develop standard criteria for selection led us to develop a scheme for rating the extent of involvement. The method is based on the classification in Table 2 and assigns a >score= of 1-3 to each type of involvement in every project. The scores range from (1) least involvement to (3) most.

- 1 = some involvement
- 2 = moderate/considerable involvement
- 3 = extensive involvement or innovative work

For example, an entry coded as SUGGEST_RES_TOPICS(2) MANAG DESIGN (1) is one that we think shows moderate consumer involvement in defining the topics for the research and rather less involvement in the actual design and management of the work.

The highest rating (3) is given to projects where consumers are either in entire control of the research process or are in a more or less equal partnership with professional

researchers. From some perspectives it can be argued that anything less is not true involvement; that there is a qualitative, rather than a quantitative, difference between this and the other two levels.

While we have some sympathy with this view, it would lead to the exclusion from the database of almost all the material we received. Moreover, it poses such a major challenge to the values and methods of established medical research that it is unlikely to be a productive model for the majority of new initiatives. For example, it may question the notion of research based on fixed (immutable) hypotheses; and it might eschew methods such as RCTs (especially blinded trials) in favour of more flexible designs which try to ensure that all >subjects= in the research benefitted from a continually evolving view on what represented the most efficacious interventions. There may be a need to debate whether consumer involvement should be aspiring to and trying to promote this type of approach, but for the present exercise we based our definition of involvement on less radical models where consumers are co-opted into research without fundamental shifts of methods and control. Most of the entries with at least one moderate (level 2) rating indicate moderate or considerable consumer involvement within this traditional framework, though a few have some more radical features.

The lowest rating is applied to projects that show some interest in involving consumers, but where the mechanisms for involvement are not widely developed. Having at least one feature of this type is the minimum criterion for inclusion on the database. Consequently, surveys of consumer views on health service provision would not be included unless there was some consumer input to the research agenda or data collection (projects would then be coded SUGGEST_RES_TOPICS and DATA_COLLECTION); or if the method of data collection allowed consumers some flexibility in their responses - for example focus groups or open-ended interviews - such projects would be coded SUBJECTS (1).

Ratings were given to all the 886 instances of involvement in the 404 projects. Level 1 ratings were most commonly awarded, 532 ratings (60.3% of the total); 332 instances of involvement (37.6%) were rated 2; and only 18 (2.0%) were rated 3.

When projects are classified by their maximum rating, 219 (54.2%) are found to only include level 1 ratings; 171 (42.3%) have one or more level 2s as their maximum; and only 14 projects include one or more level 3 rating. Eighty five projects had the minimum criterion for involvement: a single level 1 rating.

The type of involvement that we have described with the keyword SUBJECTS posed a number of problems for the project team and highlights a number of difficulties in rating the level of involvement. It could be argued that projects whose only form of involvement is described as SUBJECTS (1) may not represent genuine instances of involvement and should not be included on the database: the descriptor is used to indicate that the only involvement is collecting information from consumers by methods which give them slightly more autonomy than respondents to a structured questionnaire. This is a more complex point than it may at first appear, as it touches on both policy for the development of consumer involvement and the uneven state of involvement in different areas of research. The policy issue is whether there is just one model for the way consumer involvement should develop. For example, is it appropriate to expect the

same type of involvement in qualitative health service research as in trials of complex physical or pharmaceutical interventions? Clearly, if one takes a very radical perspective and only recognises involvement as active participation in the research process, then the work we have coded as SUBJECTS (1) should not be included, regardless of context. The more pragmatic approach, which we have adopted, is that different routes to greater consumer involvement may be appropriate for different fields of research; and need to be recognised as such. Increasing the power of research subjects to report and question their experiences may be the only way to start increasing involvement in some types of trials research. The novelty of consumer involvement in most types of medical research, and the incredulity and hostility which our requests for information provoked in some quarters, made us very reluctant to exclude reports of projects where there was at least some evidence of an interest in involvement, even if this did not take very radical forms. The coding SUBJECTS (1) was the means of including such work.

The need to judge the type and level of involvement in context meant that the same type of activity might qualify as an instance of involvement in one type of research, but not in another. Again, this applies especially to those activities which might trigger the keyword SUBJECTS. For example, the rating SUBJECTS (1) might be given if a clinical trial made efforts to collect and respond to the views of its subjects with focus groups and in-depth interviews. However, the use of such methods by qualitative research, where they are standard, might not be regarded as consumer involvement, unless there was an explicit commitment to use them in this way.

Because of the difficulty of achieving reliable, context sensitive ratings, the scores that are mentioned in this report have been removed from the public version of the database. This was done at the request of the Steering Group. The project team have mixed views on the issue. Including the ratings would give some, albeit crude, indication of the extent of involvement in each project. However, as there are no agreed standards on which to base or defend the ratings, contributors to the database could reasonably dispute our judgements and, in many cases, question whether we have sufficient information to arrive at these scores.

4.6 Who are consumers?

There was a second concern when selecting material for the database: whether the people involved in the research should be regarded as consumers?

As already mentioned, this is predominately an issue that arises from the increase in large professionalised consumer groups with very broad based constituencies and in some cases full-time research staff. This is a major issue when faced with the vast volume of research undertaken by CHCs - especially their many consumer surveys. If we included all such work it would not only swamp the database, but raise the question why we have not including the enormous number of similar studies undertaken by service providers and market researchers acting on their behalf.

Whether such work should be included is a matter for debate. In support of its inclusion it can be argued that a CHC will generally have control over which topics it selects for surveys and audit. Moreover, they often manage and design the research, collect the data and analyse and write up the results (although admittedly sometimes at the behest

of a Trust, with the assistance of professional researchers). The theoretical, rather than numerical, argument for exclusion is that a CHC only functions as a >proxy= consumer i.e. as a group which has consumer interests at heart but who, because it is in a statutory position vis-a-vis both the citizenry and health care, should not be counted as a >real= consumer.

We have tended to favour the latter position and only include CHC work when it reflects the voice of a distinct group of health care consumers - either by including them in the management and design of the research; or by collecting information from consumers in ways which allow them to have some control over the ways their views are recorded and reported. Figure 2 shows some of the guidelines that were used to detect distinctive >consumerist= features when selecting material from the NACHCEW archive. That said, it should be noted that not all the CHC entries on the database will have been selected in this way. Material that we received directly from CHCs, like material we received from other organisations, will not have been screened so rigorously, but will have been included so long as it demonstrated some evidence of consumer involvement.

The advantage of using the more rigorous criteria in Figure 2 is that it attempts to distinguish between the involvement of >proxy= and >real= consumers. For the same reason, we decided that it would be useful to add a further classification to describe the type of organisation submitting the entry (see Figure 3). Organisations are grouped under headings such as: medical, academic and local authorities. These groupings were included in the version of the database used for the analysis, but removed from the release version because we frequently had insufficient details for reliable classification. Although these groupings are absent from the database, users are encouraged to look at the organisational base of the project originators as a guide to the context in which the involvement takes place. For example, even though a database entry may not list many specific types of involvement, the work might have been done by a type of organisation which is likely to imbue all its activities with a general interest in involving consumers.

The numbers of each type of organisation amongst the database entries are shown in Table 4. Community Health Councils account for the highest proportion of entries (24.8%), followed by medical research and provider units (20.0%). Consumer organisations, of all types, were also responsible for 25.2% of the entries. The predominance of CHC projects may be due to their relative accessibility in a central archive, but it also reflects the high level of consumer oriented research amongst CHCs.

Figure 2: Questions and guidelines for project team members when selecting CHC projects from the NACHEW archive

1. Should CHC members automatically be regarded as consumers/lay people; and all examples of their research be regarded as relevant?

We should probably exclude works where a CHC is acting as an official body; i.e. as part of the NHS, especially those where it is monitoring service provision, but include projects where it collaborates with other groups which directly represent consumer interests. Those projects where CHC members are involved because of their own role as consumers of health services seem strong candidates for inclusion.

2. Is the CHC >visit= a piece of research?

A significant minority of projects are described as CHC members **visiting** health service institutions to review service and conditions - some of these may be carried out in order to meet statutory requirements; others may be prompted by patient complaints. Some of these visits are quite ingenious pieces of research. They can include extensive interviewing, tracking/accompanying patients through the system and a number of other data collection techniques that would not be out of place in academic qualitative research. These seem worth including, though there are possible objections. There is no argument for including visits that are no more than a general inspection.

3. Should CHC research be included because the time/commitment/philosophy of its members enables them to use methods, such as lengthy observation and patient tracking which are not often used by professional researchers? It can be argued that the consumer involvement makes the research distinctive because it enables the use of innovative and ingenious methodology.

4. Does CHC work involve consumers/patients in different ways to medical research? If so there is a case for its inclusion.

5. Is the standard CHC service evaluation survey any different from a professional/commercial survey? If not, it probably shouldn't be included.

6. Can CHC consultation exercises on service planning provide models for setting research priorities?

These models are sometimes set out in CHC handbooks. We should include the more ambitious, innovative and better documented examples.

Figure 3 : A Classification of Types of Organisation

1. NHS Trusts, other medical >provider= units and administrative and research units within the NHS
2. Academic bodies
3. Medical Charities
4. Large, National, Consumer/Self Help Groups
5. Community Health Councils and related organisations
6. Local Authorities and related agencies/projects
7. Medium and small consumer groups - often local and non official

Table 4: A Classification of Organisations in Projects on the Database

Organisation type (and code used in database)	N of entries	Percent of entries
Medical - includes provider units, health authorities and research in university hospitals (1)	81	20.0
Academic (2)	71	17.6
Medical charities (3)	40	9.9
Large self-help groups and consumer organisations (likely to have at least several paid employees) (4)	55	13.6
Community health councils and related organisations such as GLAHC (5)	100	24.8
Local authorities and agencies run by local authorities (6)	10	2.5
Medium and small consumer groups and self-help groups - with very few or no full-time paid employees (7)	47	11.6
All types	404	100.0

5. ORGANISATIONS AND CONSUMER INVOLVEMENT

The database enables us to >map= the types and levels of involvement achieved by different types of organisation and to note the types of initiative they can support. The type of initiative is not recorded as such, but the type of database entry (see Table 1) is a useful proxy. When, as in Table 5, we look at the type of database entry by the type of originating organisation, we see that academic units, large support groups/consumer associations and local authorities are least likely to record examples of involvement in pure research settings - for example they will report projects focussed on dissemination and service planning.

Table 5 also shows that two types of organisation, medical charities and the smaller self help groups, are most likely to have supplied descriptions of the general work of the organisation rather than reports of specific pieces of research. For the larger organisations this may be because they commission and support too many pieces of research to report each separately. For the smaller groups this may be because they are not conducting any research as such, but are trying to influence research agendas or support research through fund-raising and encouraging their members to be research subjects.

Table 5: Types of Database Entry from Different Organisation Types

Type of Database Entry	Type of Organisation N (and percentage) of entries of each type							
	Medical	Academic	Medical charities	Large support groups and consumer assocs	CHCs etc	Local authorities	Self-help + support groups	All
Research project	55 (64%)	36 (49%)	23 (56%)	27 (51%)	74 (74%)	3 (30%)	28 (60%)	246 (60.9)
Research programme	2 (3%)	3 (4%)	3 (8%)	5 (9%)	2 (2%)	0	2 (4%)	17 (4.2)
Inform research agendas	1 (2%)	1 (3%)	1 (3%)	0	0	0	2 (4%)	5 (1.2)
Organisation or individual	4 (5%)	3 (4%)	8 (20%)	6 (11%)	0	0	9 (19%)	30 (7.4)
Dissemination	8 (10%)	8 (11%)	1 (3%)	6 (11%)	3 (3%)	0	6 (13%)	32 (7.9)
Study of involvement	0	1 (1%)	0	7 (13%)	3 (3%)	0	0	11 (2.7)
Service planning initiatives	9 (11%)	9 (13%)	2 (5%)	4 (7%)	18 (18%)	7 (70%)	0	49 (12.1)
Systematic reviews	0	2 (3%)	1 (3%)	0	0	0	0	3 (0.7)
Developing instruments	2 (3%)	8 (11%)	1 (3%)	0	0	0	0	11 (2.7)
All types	81	71	40	55	100	10	47	404

Table 6 considers the levels of involvement associated with each type of organisation. The results are presented in four ways. Column A shows the average number of different types of involvement in the projects - an indicator of the breadth of involvement; column B shows the average rating per project when the levels for each project are summed (e.g. a project with ratings INFL_AGENDAS(2) SUBJECTS(1) REVIEWING(2) would be scored as 5) - this could be read as a measure of the overall volume of involvement; column C shows the average rating of all instances of involvements (an indicator of depth or intensity?). Column D notes the proportion of the projects that have at least one rating higher than level 1.

Both the overall level and number of types of involvement are, on average, greatest for initiatives run by local authorities and the smaller consumer/self help groups. Both community health councils and medical charities get the lowest average ratings. Community Health Council projects may have been down-rated by our decision not to count their exercises as involvement per se - but also because much of their work tends to employ conventional survey methods which have not been counted as consumer involvement unless they have some additional, more open-ended form of data collection. Work by medical charities also tends to get the lower ratings because of its use of conventional methods: much of what they commission and support is medical research where consumers are only involved as research subjects.

Table 7 examines the types of consumer involvement in initiatives from the different organisations. The patterns of involvement are broadly similar, but there are some differences worth noting. The medical charities and self-help groups are less likely to be directly involved in activities where consumers are involved as subjects. In the case of some larger charities this is because they will tend to commission rather than conduct research. In the case of the smaller self-help groups, they will not always be able to commission or conduct research, but can provide other kinds of support, such as fund-raising or recruiting subjects for research. However, when these smaller groups do conduct research, it tends to have an above average input from consumers in the design and management stages.

Community Health Council work tends to be distinctive in concentrating on service review and audit, where there is limited opportunity for consumer involvement. Many of these projects will be coded as either SUBJECTS (1) - work where respondents have some opportunity to express their views outside a structured survey, or AUDIT_MONITORING (1) - work which takes some account of consumer feedback in service review.

6. CONCLUSIONS

The aims of the project were to develop a database that would map the field for the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme and provide consumers and researchers with a means for identifying recent initiatives and people who are active in the field.

Several methods were used to find material for the database. Some of the more successful were postal trawls of health charities, patient support groups, NHS R&D coordinators and conference presenters and attenders. Searching bibliographic databases was far less successful, largely because there were no standard descriptors or keywords for consumer involvement to help locate relevant material. Searching is further complicated by the difficulty of knowing where to find details of consumer involvement in the standard protocols for summarising and abstracting research.

The version of the database being distributed with this report contains approximately 430 entries. While we believe that the material on the database reflects the full range of consumer involvement initiatives and includes most of the most innovative work currently taking place in the UK, we are less certain that the selection is statistically representative. The most likely sources of bias are the lists of contacts used for the mailings; the use of different types of sources for different types of organisations; and the possibility that certain types of groups have systematically under-reported due to lack of interest or a (mis)perception that their work was irrelevant to the exercise.

A classification of types of involvement was developed by the project, both to aid the selection of suitable material and provide users of the database with standard search terms. The development of this classification was far from straightforward and it would have benefitted from the results of one of the exercises the database is intended to support - the creation of guidelines for consumer involvement. In the absence of such guidelines, a classification was built around the stages of the >classical= model of research. For example, consumer involvement in project design was distinguished from consumer involvement in data collection, and from consumer involvement in data analysis etc.. The classification had to be expanded to take account of consumer activity in the pre-research phase, such as in agenda setting and commissioning; and in the post-research period, such as the dissemination and implementation of results.

Basing the classification on this model of research limited its ability to describe some of the more radical initiatives which question the traditional approach to research design, but pursuing these questions theoretically and devising an alternative was well beyond both the brief and resources of the project.

The classification was developed into a system to rate the extent of involvement in each of the database entries - though these ratings are not included in the public version of the database. When applying these ratings and summarising the results it was clear that the type and extent of involvement was related to the size and nature of the organisation conducting the work. Hence the project produced a short typology of organisations to reflect their potential to involve consumers in research.

These efforts at classification need further thought and a firmer grounding in different models of consumer involvement. On the one hand they may be too detailed for wider use, on the other hand, they may be too crude or ill-founded to convey some important distinctions between different types of involvement. We hope this work will be carried forward. A widely accepted set of descriptors would increase both the profile and accessibility of this field.

Finally, we hope that the database will prove useful and encourage people to develop projects that involve consumers in research. We also hope that it will prompt researchers and consumers to supply details of similar work for future versions. At the time of writing it is unclear whether the database will be released again on disc, but the aim is to have a >live= version running on the Internet before the end of 1999. People with details of new projects, or amendments to existing entries, will be able to supply material on-line. In the meantime we apologise for any errors in the existing version and urge you to contact The Support Unit at The Help for Health Trust (their address is in Appendix B) with any amendments or new entries.

REFERENCES

Carr-Hill et al (1989) The NHS and its Customers, Centre For Health Economics, University of York.

Department of Health (1998) Research - What=s In It for Me? Conference Report, Standing Advisory Group on Consumer Involvement in the NHS Research and Conference, Department of Health, London (13603 1P 1.2k Aug98 BAB).

NHS Executive (1997) Patient Partnership: What=s in it for Me?, Conference programme, workshops and exhibitors. NHS Executive, London, May 1997.

Oliver and Buchanon (1997.1) Examples of Lay Involvement in Research and Development - Report. The EPI Centre for the Evaluation of Health Promotion and Social Interventions, London, 1997.

Oliver and Buchanon (1997.2) A Bibliography of Documents Recording Lay Involvement In Research. The EPI Centre for the Evaluation of Health Promotion and Social Interventions, London , 1997.

APPENDIX A

Typical Data Collection Forms and Covering Letter Used for the Database

(Forms and letters were varied to suit different data collection methods and different groups of respondents)

THE UNIVERSITY *of York*

Consumer involvement in research - A database for the Standing Advisory Group on Consumer Involvement in the NHS R&D Programme.

Please use this form to give details of projects involving lay people in commissioning, designing or conducting medical or health services research, in any capacity. A wide range of activities can be included, from projects that have been entirely conducted by lay workers to work undertaken by professional researchers based on concerns suggested by lay people.

Please send details even if you are not entirely sure whether or not the work should be included.

Please use a separate form for each project, make copies as required or contact the address at the end of the form for more copies. We would be grateful if you would pass copies to anyone who you know is involved in this type of activity.

Your replies will be put onto a database that will be nationally available and will help spread awareness of lay involvement, aid networking and suggest models for further work.

Project details (project can be current or any date back to 1985)

Title:

Aims/Brief description of the research:

(As well as the aims, please include details of the setting for the research (e.g. general practice) and the groups and activities being studied.)

Type and degree of lay involvement in instigating/designing/conducting the research:

(Who did what?)

Please tick here if black or other ethnic minority groups have been involved in the work.

These projects are being collated by a separated project run by Mark Johnson at the Centre for Research in Ethnic Relations (Warwick), but the forms should still be returned to York.

PTO

Project Duration/dates:

Start: End:

Funding:**Funding source:****Type of funding:**

(One-off grant, programme, recurring etc..)

Main features of Design/Methods:

(E.g. survey, randomised controlled trial, focus groups)

Publications/reports:

(Any reports or publications from the work that are publicly available)

Contact name (and name of group, if appropriate):

Address:

Tel:

Please complete this section if your organisation has no material to include on the database

We have no material for the consumer involvement database (please tick)

Organisation name:

The form should be returned in the SAE provided to:

Roy Carr-Hill

Centre for Health Economics

University of York

York YO1 5DD

A member of the project team may contact you for further details.

Many thanks for your help.

*Fname+
*Orgn+
*Addr1+
*Addr2+
*Addr3+
*Addr4+

Dear, *Title+ *Surname+

Your Organisation and Lay Involvement in Health Research

The NHS R&D programme is hoping to increase lay involvement in the medical and health services research that it funds. It also wants to more generally increase awareness of the potential of lay involvement at all levels of health related research. Amongst the measures to achieve this end the programme has commissioned the Centre for Health Economics (York) and the Public Health Resources Centre (Salford) to compile a database of past and current work where lay people have an active role in instigating, commissioning, designing, or conducting research; or have assisted in the dissemination of research findings.

The aim is to make the database publicly available on a web site and on CD-ROM so that it will hopefully networking, inspire new projects and approaches and generally further the cause of lay involvement.

Do you know of any work from organisation that should be included on this database? If so, would you please describe its basic features on the attached form. A wide range of material is of interest: from projects where part of the research design or fieldwork was carried out by lay people to cases where lay people have recommended areas for research, made representations to funding bodies, or otherwise been involved in research commissioning.

Please send details even if you are not entirely sure whether or not the work should be included; after all, one purpose of the project is to clarify the range of activities that count as lay involvement. Please reply even if your organisation does no work of this type. This will save us sending reminders or trying to contact you by phone.

Finally, thank you very much for reading this and, hopefully, sending us material for the database. If you have any questions about the exercise, want more forms, or would prefer to supply project details over the phone, please contact Roy Carr-Hill (01904 432306), Paul Dixon (01423 860753) or Edwina Peart (0171 612 6631).

With best wishes,

Roy Carr-Hill
Reader in Medical Statistics

APPENDIX B

Parallel projects

Two other projects were commissioned by the Standing Advisory Group on Consumer Involvement at the same time as this database.

The Centre for Research in Ethnic Relations (University of Warwick) constructed a similar database concentrating on the involvement of black and ethnic minority consumers in research. More details can be obtained from:

Anne Shaw
The Centre for Research in Ethnic Relations
University of Warwick
Coventry
CV4 7AL
01203 524232
Email CRER@Warwick.ac.uk

A team from The Department for Policy Research in Engineering Science and Technology (PREST) compared lay and professional perceptions of the medical research agenda.

PREST
University of Manchester
Oxford Road
Manchester
M13 9PL

The database will be maintained by:

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

Tel:01962 849100