

LISTENING TO PEOPLE

User involvement in the National Health Service - The Challenge for the Future

Ros Levenson and Nikki Joule

**The Greater London Association of Community Health Councils
100 Park Village East, London, NW1 3SR**

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The Greater London Association of Community Health Councils
100 Park Village East, London, NW1 3SR
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LISTENING TO PEOPLE:

User involvement in the National Health Service - the challenge for the future.

Introduction

The National Health Service (NHS) may be unique as a public institution in the degree of enthusiasm that the general public feels for its continuing existence. While political parties vie for credibility as to who can best safeguard its future, at a local level there is increasing concern about not only the NHS's survival, but also how it can change and develop in order to most fully reflect local needs.

Since their establishment in 1974, Community Health Councils (CHCs) have sought to improve health services by encouraging the public to become interested and involved with the NHS in a variety of ways. In many instances, that commitment to user involvement has not been matched by enthusiasm or commitment from statutory authorities, such as District Health Authorities (DHAs).

However, there is now an apparent upsurge in interest, at least at the rhetorical level, in encouraging and enabling users and potential users to make their voices heard. This trend has been encouraged by the implementation of the NHS and Community Care Act 1990, which, as Hogg and Winkler (1989) have noted, means that "a strong independent user voice is more important than ever".

The challenge for the National Health Service of the future is to involve users and potential users in planning the service and monitoring and evaluating

it. This paper examines some of the apparent obstacles to meeting that challenge, and some of the current models of user involvement. It also outlines some interesting initiatives from London Community Health Councils that may enhance user involvement in their own work, and it outlines some of the fundamental principles necessary for making participation a reality.

Much work remains to be done on how user involvement can be improved, and there is certainly some evidence of new and determined attempts to reach out to communities. The Greater London Association of Community Health Councils (GLACHC) is planning detailed work in this area. Meanwhile, this paper is an attempt to outline the current situation.

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USER INVOLVEMENT: SOME DIFFICULTIES

Why is user involvement problematic ?

It is certainly understandable that there is a great deal of concern about how to involve users in shaping their Health Services. The task of collecting and collating diverse views from people who may be unaccustomed to making their views known is not an easy one. What is not so understandable is the impression that, in spite of the fine rhetoric, some managers are less convinced than others about the basic premise that it is worthwhile to involve lay people in planning and commenting on their own Health Service. For some people, the debate is still stuck at whether to involve users. Others agonise about how much to involve them. More progressive managers have moved their concerns on to the techniques for doing so effectively.

However, the real issue for making user involvement a reality is a fundamental commitment to equality between those who work for the NHS and those who use it. It is important to be clear that an assumption of equality is not a negation of the skills of either clinicians or managers. It is simply a question of recognising who is there for whose benefit.

Representation

Once a basic commitment has been made to the desirability of involving users in shaping and evaluating their health services, several obstacles remain. Foremost among these obstacles is an anxiety about how the views of users are to be represented. Many managers appear to fear user involvement because it is not possible to involve all users all of the time on all the issues.

It is possible that this anxiety derives from an underlying unease about the difficulties of getting close to community views in the absence of formal, democratic channels. In so far as that is the problem, it is understandable, and there are real limitations on the extent and nature of user involvement within a system that is now less directly accountable than ever before in the history of the National Health Service.

However, it is difficult to believe that it is a worry about health service democracy that stands in the way of user involvement to any significant extent, particularly since many NHS managers are lukewarm or even frankly hostile to the idea of an accountable, democratically run NHS. It is more probable that

there is a conceptual confusion between the idea of representation and the idea of user involvement.

User involvement does not depend on finding the holy grail of perfect representation. It does not actually fit into ideas of perfection at all, since perfection implies a finished product, and involving users is, in its very nature, an unfinished business - a dynamic *process*, rather than a static end-product. Therefore, it is reasonable to aim for a goal that we could see as *good enough user involvement*, which is good enough simply because it is the best possible at a given time, and moreover, is not to be seen as a once-and-for-all achievement.

The quest for user involvement is best seen as a mosaic or a jig-saw. The more pieces there are, the better and clearer the picture will be, though it is possible to get a reasonable overview even if some of the pieces are missing, particularly if there is some awareness of what kind of pieces may be missing.

The user... or users

The anxiety about "getting it right" manifests itself in a variety of ways. One manifestation is seen in the quest for the perfect user (singular), who can be taken as a distillation of users (plural) in general.

Presumably, it is that kind of agonising that led to the following statement, quoted from the notes of workshops to discuss services for elderly people held by North East Thames Regional Health Authority in the summer of 1991.

How do we establish what the views of users are when any one "user" will not represent all issues.

It is, of course, true that one user will not represent all issues. Nor will one doctor, one nurse or one manager, but there is rarely the same unease about that limitation.

Sometimes, the desire for a single user voice produces a rather plaintive note. In its interesting and introspective Communications Plan (1991), Hampstead Health Authority laments:

The views of Hampstead people about the health care they have and/or would like to receive are

undoubtedly complex, contradictory, if not incoherent.

Leaving aside the gratuitous insult about the alleged incoherence of Hampstead's population, we must wonder whether a multiplicity of views is, in itself, seen as an aspect of incoherence. Also, as is observed in the same document:

There is no available blue-print as to how to build worthwhile links into the local community in a way which will facilitate the influence of consumer views on the Authority's policy-making.

The value of subjective experience

A further obstacle in the way of genuine user involvement is that the views of users are necessarily subjective. This is anathema to the world of medicine, which locates itself in a scientific, and therefore apparently objective framework. As Danielle Piette sums up Bachelard's work on lay and scientific approaches:

Scientists work on facts with as much objectivity as possible; lay people work on perceived events (subjectivity). (Piette, 1990)



This tension between the scientific, with its claims to objectivity, and the lay, with its subjective basis throws light on some recent bizarre observations.

In a recent NHS Occasional Paper *Measuring Quality - the Patient's view of day surgery*, the Audit Commission make some interesting observations. In a table entitled *Examples of Quality Indicators for Day Surgery*, the view of the patient and the professional are shown in separate illustrations. (see below)

What is interesting is that the professional is shown to have views on "improvement in health status", whereas the patient, who is depicted with a telling cloud over his head, is credited only with knowledge about "perceived" improvement in health. If the patient is not given equal status in knowing whether or not their health has improved, what hope is there for involving health service users on an equal basis with the professionals.

Another revealing insight into the phobic anxieties about subjectivity came from a speaker at a meeting of the Patients' Forum (September 1991) who felt that people who used the National Health Service frequently had a vested interest in it and were, therefore, not representative. This view led the speaker to believe that what was needed from users was "informed but uncommitted" views.

Unless managers shift their attitudes towards the public so that they truly value what people have to say, the potential benefits of involving users will remain unrealised.

	Condition	Structure	Process	Outcome
The patient's point of view 	<input type="radio"/> patients' health and social background	<input type="radio"/> perceptions about design and provision of facilities <input type="radio"/> adequate parking	<input type="radio"/> provision of written information for patients <input type="radio"/> perceived attitude of staff <input type="radio"/> adequate pain control <input type="radio"/> waiting time <input type="radio"/> use of community services	<input type="radio"/> time in bed at home afterwards <input type="radio"/> time off work <input type="radio"/> perceived improvement in health
The professional point of view 	<input type="radio"/> patients' health and social background	<input type="radio"/> existence of day-case facilities (preferably with operating theatre) <input type="radio"/> use of specially trained nurses for sessions involving children	<input type="radio"/> firm date for admission <input type="radio"/> waiting time <input type="radio"/> patients who did not attend <input type="radio"/> good patient selection procedures <input type="radio"/> provision of written information for patients	<input type="radio"/> extent of post operative infection <input type="radio"/> un-planned re-admission <input type="radio"/> emergency treatment following procedure <input type="radio"/> improvement in health status

SOME CURRENT MODELS OF USER INVOLVEMENT

It is widely accepted that there is much to be learned about how users can be involved in service planning. Some Health Authorities admit their ignorance and see the need to learn for the future. As Bromley Health Authority stated in its Draft Purchasing Plan for 1992-3/1994-5:

This is the District's first experience of how best to ensure the maximum involvement of the parties aforementioned. [Consumers and others] The consultation period will therefore be used as much to learn how we can most effectively consult.

Unfortunately, this degree of humility is not universal, and there are a number of models of involving users at present, which are, in themselves inadequate or even unhelpful. What follows is an attempt to sketch out four existing models. It is fully recognised and accepted that these models are simply models, and as such they are rarely found in these crude forms. Nevertheless, it may be helpful to examine them in order to see what lessons are to be learned, and what the possibilities and limitations of the models are.

Model 1

The "tell me you love me" approach

This is the approach that tries to "get close to the user", at least in the sense of trying to ascertain the level of satisfaction felt by existing users. Typically, this is done through surveys, among which patient satisfaction surveys are particularly favoured.

Many Health Authorities commission their own surveys in order to determine levels of patient satisfaction. Recently, the National Association of Health Authorities and Trusts (NAHAT) conducted a national survey in conjunction with the Health Services Journal. Unsurprisingly, it found that 87% of people were satisfied with treatment received as hospital in-patients within the last two years. The percentage of respondents who generally have a good opinion of the NHS had actually risen to 75%, an increase of 10% compared to 1990 (NAHAT 1991). The figure for satisfaction in London was lower, at 62%. Even so, the results enabled Philip Hunt to comment:

"It's good to know that the public have such a high opinion of the NHS."

Although some surveys claim to seek a range of views, their concern with "satisfaction" is illuminating. We rarely, if ever, hear of a "patient dissatisfaction" survey whose aim is specifically to identify shortcomings in a service. The NAHAT survey, for example, asks a number of questions about levels of satisfaction, but no questions about the specific aspects of the NHS that patients may find unsatisfactory, or areas that they could suggest for improvement. In general, patient satisfaction surveys determine numbers, rather than getting at the more interesting, and more difficult area, of the reasons why people feel as they do about their services.

It is a serious limitation of patient satisfaction surveys that, by definition, they can only get at the views of people who have been patients (and survived the experience). The level of enthusiasm for a service would clearly be less among those who were on long waiting lists for treatment, or among people who were disaffected with the nature of the treatment on offer and who, therefore, had sought alternative kinds of help.

In any case, there appears to be a paradox whereby the poorer a service is, the greater the level of reported satisfaction with it. The reasons for this are complex, but they may include a sense of relief and gratitude at having obtained treatment at all, particularly in a climate of scarce resources. It may also be significant that many patients feel great sympathy for the pressures under which staff work, and they do not wish to upset them by critical comment. The desire to please hard-pressed staff and to express solidarity with their difficulties may well influence expressed levels of satisfaction.

It may also be the case that some people fear reprisals on them in their future contact with service providers. Although this fear is extremely unlikely to be borne out in reality, it is an understandable fear, particularly in people who are dependent on a service for long term care.

It is generally the case that the "tell me you love me" approach is mainly concerned with hotel issues - what Pollit (1988) has termed "the charm-school-and-

better-wallpaper" approach, and not on outcomes or on the treatment itself. The lack of user involvement in commenting on clinical issues has been noted by many commentators, including Hogg (1988).

It is also a problem that surveys generally start with an agenda that reflects the concerns of the professionals rather than the users or potential users of services, and that limits their scope and undermines their impact in terms of involving users. In so far as this approach may be supplemented with focus groups or other techniques borrowed from the world of market research, it may be possible to move away from the narrow confines of surveys which merely measure satisfaction with a given service while failing to challenge the basis of the service, but unfortunately the more limited model is often the major plank in apparent attempts to involve users.

Model 2

The Kill Them With Kindness Approach

This approach aims to redress the wrongs of the past, when users were left out in the cold and it tries to involve users indiscriminately. Typically, this approach will consist of bombarding the Community Health Council, user group or individual with reams of paper. The documents are often not relevant, and when they are, they may be so full of jargon as to be unintelligible.

It is also characteristic of this approach that a well meaning key person in the management will invite lay people to an impossible number of meetings. Sometimes, lone users or voluntary organisations, or perhaps the CHC, are invited to be token lay members of committees on which they are always and inevitably outvoted, or on which the user perspective is seen as an alien graft on to the "real" business of the meeting.

The experiences of lay representatives on Local Research Ethics Committees (LRECs) were reported at a workshop held by the North West Thames Regional CHCs Liaison Committee in 1989. Some reported being made to feel extremely uncomfortable, with their "observer" status being stressed during the meetings and the issue of confidentiality being constantly raised to question their right to be involved. One member even reported that her papers were taken away from her at the end of the meeting.

A variation on the theme is to convene meetings at times that suit the medical members of a committee, irrespective of its suitability for others. For example, meetings about maternity services have sometimes been suggested at 8.30 in the morning, to the consternation of the lay member with a small baby.

This kind of double-think, where the rhetoric suggests that users are more than welcome while the practice indicates that they are less than welcome is at the root of quite a bit of misunderstanding. Unless the attempt to involve users is properly thought out and appropriate in the means used to achieve the ends, it is an endeavour that is all too likely to end in tears.

Model 3

The Godfather approach

This consists of managers trying to identify a "community leader", and then diverting all attempts to involve his or her community through the identified leader. An optional extra to this approach is that the cynical manager may try to incorporate the Godfather so far into the system that they lose their erstwhile community roots, and may lose the trust of the community from which they are drawn.

There are individuals and they can contribute significantly to the process of user involvement. However, the over-reliance on individuals is a dangerous path to tread if it leads to the inappropriate use of certain people to the exclusion of others. It is also a rather pernicious approach in the selective way in which it is used. Most frequently, it is used as the conduit to Black and minority ethnic communities, which are seen as homogeneous in a way that white communities are not - a view which is very far from the truth. Managers sometimes retreat into the Godfather approach out of fear and ignorance, when they feel unsure how to negotiate the different values, customs and opinions that exist within communities. The appeal of dealing with one or two people becomes a tempting alternative to dealing with many individuals and groups, who may differ in their needs and opinions as much as they share in them. The Godfather approach may operate at an informal level or it may lead to an institutionalised form, where individuals are given formal recognition through a place on a significant committee or Board.

This kind of tokenism is inherently racist in its consequences, even if that is not the intention of the

managers. It is an approach which is likely to alienate and offend.

Variations on the theme can be used in respect of elders or people with disabilities, who can also be perceived as homogeneous in their respective views. However, no system which relies too heavily on channelling communication through an individual can be adequate to enable proper involvement of users. It is an unfair imposition on the community leader who is selected for the task and it is an inadequate means of making links to the communities in question.

Model 4

The Puppet Show Approach

This model implies a recognition of the problems of representation, which have been discussed earlier, but surprisingly, some of those who are most worried about the problem seek to solve it by ignoring the difficulties and setting up a consultative group of their own choosing, and under their own control.

In this approach, the Community Health Council is likely to be overlooked or explicitly dismissed as inadequate and unrepresentative. In its place, some people choose to set up a Patients' Council, or a group with a similar title to give the view of the man or woman in the street. These groups may be doomed to fail, as they are even less able than groups that have genuine origins in the community to be able to grapple with the inherent difficulties of putting forward views that accurately represent local concerns. The worry is that in the process of their shortcomings becoming evident, they can do a lot of harm to the proliferation of groups and individuals who should be involved in independent discussions with purchasers and providers.

This model is typified by Jim Corbett, Contracts and Commercial Manager of Barnet General Hospital. Corbett is an ex-CHC Secretary, a poacher turned gamekeeper. According to a report in the Health Service Journal (Tomlin 1991), Corbett is reported to have suggested at a meeting organised by the National Association of Health Authorities and Trusts (NAHAT) on "Contracts and Quality - the patients' perspective" that:

...there were few other bodies in the NHS less representative of the public, [than CHCs] harbouring sectional interests as they did.

Because of this, his hospital had decided to by-pass the CHC structure and was setting up a patients' panel. It will be interesting to see how these groups are to be constituted. It will be particularly interesting to see what spread of membership is achieved, and whether the panel will take the easy option of involving established groups, which may often have as much of a stake as providers as they have as users.

It remains to be seen how such panels will operate. Will they be able to reach out to a wider notion of community than hitherto? Will they have access to the information that they need? Will they be able to influence the agenda, or will they be restricted to commenting on matters of the management's choosing? And above all, will they be heeded or even allowed to continue to exist if they do not behave in an obedient puppet-like manner? To be fair, we do not yet know the answers to these questions, but it would be moderately surprising if a hand-picked group considering a pre-set agenda would ever be too threatening; and if they were, it would be deeply surprising if the convenors of such groups would remain enthusiastic about their continued existence. Community Health Councils are better placed to do the job for which they are set up by statute, and they would do well to be vigilant about the activities of puppet groups.

GOING FORWARD TO INVOLVE USERS

In spite of the inadequacies of the models discussed above, there is a widespread desire to involve users, if only the techniques for doing so were more fully developed. If progress is to be made, more empirical work will have to be done in order to test out what works and what does not. It is also essential that those who wish to involve users fully and constructively must appreciate that their task is not finite, will never be complete, and that there is no single correct way to proceed. What follows is a brief attempt to look at some of the ways forward.

The role of Community Health Councils

The resource question

Community Health Councils have been the butt of a lot of criticism, much of it self-criticism, some of which is appropriate, and has been an attempt to push forward to a more effective mode of working. However, it is a matter of serious concern that statutory powers have been diminished as a result of recent legislation. It is also disturbing that CHCs have not been given the tools to do the job, in terms of finance. Most CHC offices run on a small staff of two or three people, with a tiny budget that pays only for those staff and for the bare essentials of running an office. The budget for London CHCs varies across the Thames Regions, ranging from £48,000 for Bexley in SETRHA to £108,000 for Parkside in NWTRHA (GLACHC 1991). Although such stark differences can be explained, to some extent, by differences in population and other factors, the variations are still significant, and it must be emphasised that even the better endowed CHCs are still operating on a shoestring.

The need to stay local

For the future, there is an overwhelming need to keep CHCs local and in touch with communities that have a sense of their own existence. In the context of possible Health Authority mergers, it is extremely important to ensure that mega-Purchasing authorities are not automatically followed by merged CHCs, as that would be against the public interest. What Allison Quick wrote in 1990 in *For Better or worse* remains true:

Smaller CHCs can provide better representation and account-ability. A merged CHC, even if granted extra members, will not have sufficient to maintain the level of representation from either local authorities or voluntary groups.

Fortunately, it seems that this view has now found favour in Whitehall and Westminster.

The need for an independent establishing body

GLACHC has argued for a long time that CHCs should be established by an independent establishing authority. In terms of being seen to be independent, it is not comfortable for CHCs to be under the Regional Health Authority umbrella. This is particularly so when CHCs had to send their responses to applications for NHS Trust status to the very bodies that are responsible for CHCs. It is not that Regional Health Authorities abuse their positions; it is simply that there needs to be a clear message about the independent nature of the CHC.

The separation of functions would also enhance the support that could be given to CHCs. At the present time, the officers responsible for the CHCs in the Thames Regions also have other responsibilities and they cannot give the time or attention to the CHCs that they might wish.

The strengths of CHCs

In spite of difficulties, it is important to recognise the significant role of CHCs in facilitating user involvement in the NHS. The traditional CHC concern with elderly people and people with disabilities, has been an important antidote to the tendency of powerful lobbies to overlook the needs of people who need care as well as cure.

The challenges for the future for CHCs

The growth of community care and the transfer of people from hospitals to the wider community poses important issues for CHCs. Community services are likely to be local authority services as well as health services and the primary responsibility for community care is to be in the hands of local government.

Because local authority members are elected, the issues of democracy, accountability and user involvement are different in that context, and need a fuller discussion than can be allowed here. However, the need for independent user-based involvement in planning and monitoring local authority services is important. CHCs may be able to do this to a limited extent on an informal basis, but formal powers are needed to make this a reality.

There is also a need to address similar issues in relation to services provided by non-statutory organisations, such as voluntary organisations. This is likely to become more important as time passes, as voluntary organisations may find that the impact of contract culture pushes them further towards a major provider role, and in some cases this could conceivably be instead of, or in conflict with, pressure group or advocacy roles.

CHCs and links with local people

CHCs generally recognise the need to raise the profile of CHCs, to broaden the membership base and to have effective working links with local individuals and organisations. There are many examples of attempts to achieve these aspirations. What follows is five examples of how some London CHCs have attempted to make links.

Example One: A systematic approach to make links with local organisations

Croydon CHC networking project

The purpose of this project is to ensure that the CHC had a high profile in the reformed NHS and could make a credible contribution to the assessment of health needs and the setting of contracts. A systematic approach was considered to be essential in order to validate the comments made by the CHC. Croydon CHC covers quite a large area, and the CHC felt that its comments could not be dismissed lightly if they came from North, South, East and West of the district, and from many different sources.

Croydon CHC decided to go forward by linking each member of the CHC with a small number of organisations. Members could then keep in regular touch with those organisations, passing on news about developments in the health services and seeking information from the organisations.

The degree of contact between CHC members and the

various organisations varies considerably and is tailored to the wishes of each organisation. In some cases, regular visits to an organisation might take place, while in other cases, a monthly phone call may suffice. CHC members record their findings, and these views, suggestions and complaints are relayed to the CHC office for action, and transferred to the CHC's computerised database.

To achieve this link, the range of voluntary and community organisations in Croydon was reviewed with a view to identifying those most likely to have an interest in health service issues. As a result, seven categories emerged: Health and Disability organisations, Neighbourhood Care Groups, Parent and Children groups, Elderly people's groups, Women's organisations, minority ethnic organisations and youth organisations. In all, 164 groups were approached.

Letters were sent in waves and organisations were asked to respond in four weeks, after which those who had not responded were followed up by telephone. Although this was time consuming, it was worthwhile as many people were interested, but had either mislaid the original letter or simply needed a reminder. A positive response was received from over 100 groups, although some did need to be assured that it would not involve attending a lot of meetings.

Early indications from Croydon are that the project is worthwhile. The profile of the CHC has risen, and this was reflected in attendance at the CHC's 1991 Annual General Meeting.

After just four months of the project, the CHC was able to extract sound data. Issues raised by the groups included the need for crisis care for people who were mentally ill, the wish of women to consult women doctors for specific health matters and the particular problems experienced by health service users who did not speak English.

The project has also significantly helped forge constructive contact with Black and minority ethnic groups and twelve of the groups participating in the project are in this category.

The CHC is also happy to note that its comments are now taken more seriously, and are not dismissed as anecdotal. As the Chief Officer of Croydon CHC, Joan McGlennon says:

A systematic approach certainly brings good results.

Example Two: Wandsworth Community Care Alliance

The CHC as broker/facilitator

The NHS and Community Care Act 1990 requires the involvement of service providers, users and carers in the drafting of Community Care plans. In Wandsworth, there was a growing realisation that the success of the Community Care Plan rested on the development of a consultation framework.

There had been attempts in the past to involve voluntary organisations in planning, the most recent being a mental health planning team which had drafted a plan for services as a bid for the mental health specific grant. Three local voluntary groups interested in mental health had been invited to be members of this team. Concern that these groups could not be representative and that they were unable to feed back to other voluntary groups, or be supported in their role, were not disputed by the Health or Local Authorities.

The issue of voluntary sector and user representation became the CHC's issue when it was suggested by the Joint Care Planning Team (JCPT) that Wandsworth CHC nominate an individual to the JCPT to fulfil this role.

The CHC accepted that in its present form, it could not claim to be the representative of either voluntary groups or local people. However, it was in a unique position to act as a broker, or to facilitate the forums that are needed to enable effective representation.

In December 1990, Wandsworth CHC was able to host a meeting of some fifty local organisations to set out impartially the requirements of the NHS and Community Care Act, to outline the timetable for its implementation and promote a discussion of the way forward for Wandsworth. The outcome of the meeting was overwhelming support for the formation of a voluntary sector Alliance to provide an independent voice on community care issues. That is how the Wandsworth Community Care Alliance (WCCA) was born.

Since its initial meeting, the WCCA has developed a working relationship with the Health and Local Authorities. It has a structure which mirrors that of the joint service area planning teams, with groups looking at issues for elders, mental health, learning disability, physical disability/chronic illness and home care. It has also set up a group to look at means

of enabling and increasing involvement in planning by Black and minority ethnic groups.

The three Authorities (ie two health authorities and one local authority) have welcomed three representatives from each group to their planning teams and three WCCA representatives to the Joint Care Planning Team. Joint Finance has granted an initial sum of money for WCCA administration and bids will be considered to provide a worker to co-ordinate the WCCA for the next year.

At the time of writing, over 90 groups and individuals are involved, and overall there is broad agreement that the WCCA has made a constructive contribution to local planning and has already been beneficial in bringing organisations together to share information and ideas.

In setting up the WCCA, the CHC saw itself as enabling effective local representation. In addition, there were a number of benefits to the CHC. These included establishing a network with and among local voluntary groups; improving the exchange of information in the locality; increasing the resources available to the CHC by sharing information and involving more groups to the mutual benefit of all; increasing the profile of the CHC and being seen to be a constructive body and gaining support on the planning teams.

The CHC also learned lessons from the initiative, such as the need to beware of jargon and "health speak" which is alien to voluntary groups and users of health services. The CHC also has established that it can be seen as an independent body, able to facilitate local initiatives or to act as a broker for such endeavours.

Example Three

Informing the local community about the CHC: Harrow CHC's approach

Harrow CHC felt that the Annual Report, if prepared in an eye-catching style, could be an excellent opportunity to reach a wider audience of Harrow people than is usual for an Annual Report. In view of the far reaching changes taking place in the NHS, it was also felt that it would be useful to produce the report in a form which people could keep at hand for reference throughout the year.

The CHC decided to circulate throughout Harrow by

using the centre pages of their local authority publication, "Harrow Magazine", which appears quarterly. The CHC was able to negotiate a very good deal for the centre spread and later added to this an additional two pages. The report was compiled with a view to easy readability, and to be interesting to the public, while, at the same time, giving information about the changes in the NHS and about local health clinics, hospitals etc, with locations and phone numbers. In this way, a ready list of useful information would be associated in people's minds with the CHC.

The Harrow Magazine goes to 78,500 homes, and the CHC was quite concerned about an anticipated rush of possible telephone calls once people read the report. While the level of work did not increase as anticipated, the number of telephone calls certainly increased, though not all at once. A steady stream of calls confirmed that having the CHC services to hand in the pull-out form has made it possible for people who might not otherwise have heard of the CHC to get in touch. People ring up and say "Are you the people I read about in the Harrow Magazine?" or "I pulled out your feature and kept it by the phone."

Another closely linked benefit was the corresponding rise in response to CHC surveys, which possibly reflects a greater awareness of the CHC.

In addition, the number of people who phone or drop in to the office just to ask for information has significantly increased, by about 15%.

Financially, this attempt to reach Harrow's population was not expensive, as the magazine printed both the glossy "give-away" versions and the copies which went into the magazine. Also, office time was saved as individual mailings were less necessary in view of the wide distribution.

Members of the CHC found it rewarding to be associated with such a professional demonstration of the work they do, and were pleased to be able to show the work of the CHC to friends and colleagues.

Harrow CHC would recommend a similar exercise to other CHCs. It certainly helped raise the profile of the CHC, and with the possible addition of a tear-off slip for use with Freepost, it could be a way of involving people more widely, and of gaining members and co-optees.

Example Four

Involving Black users: Camberwell CHC's approach

Camberwell Community Health Council became concerned that its well established Ethnic Minorities Group, despite producing a number of thick documents, achieved few changes. Services remained much the same, and the Committee consisted of mostly white people. This was the situation that Camberwell CHC were determined to alter.

In particular, the commitment to bringing Black people into the work of the CHC necessitated a radical re-think of what the CHC's purpose was. As Camberwell CHC's Chief Officer comments:

In practical terms, this means making the demands of Black and Minority ethnic organisations our demands and fighting with them to achieve their objectives. It means challenging Health Authorities on issues such as the high numbers of Black people on locked psychiatric wards, and the poor access to women consultants. It means that we are working to achieve more than "fair play" and "fair access" - we want racism and sexism made unacceptable in the NHS because they are repugnant and they distort Health Service planning and make services unavailable, unacceptable and inappropriate.

With this commitment, the question was how to work in ways that did not alienate or seem irrelevant to the local community. One of the ways that has proved most successful has been the opening up of the Ethnic Minorities Group to be used by the community for single issue campaigns and as a catalyst to other sections of the CHC. The Group has a large floating membership, and while the CHC observes regulations on co-options, it takes a creative approach to involving local people who are interested in being involved in ways that are important to the people themselves. It is the experience of Camberwell CHC that a single issue focus enables many people to become actively involved, who would otherwise be alienated by a large and seemingly irrelevant agenda.

Another successful means of involving people in both work relating to Black and minority ethnic health issues and to work on mental health issues has been the encouragement of complainants to participate in the ongoing work of the CHC.

The CHC is also trying to dismantle some of the many

barriers which it sees as excluding people, such as excessive bureaucracy and the use of jargon and other language that people find unhelpful.

Above all, the CHC asserts that the key to involving local people is to work to the agenda that they define as important and not to simply try to impose an agenda that does not reflect their needs and experiences. In the words of the Chief Officer:

The diligent work with individuals and organisations in Camberwell led to a spectacular change in the use of the CHC. Instead of a handful of Black and minority ethnic people using the CHC, now 80% of our clients are from those communities, leading to a massive increase in our work and huge new demands on our services. It is a validation of our organisation.

Example Five

Older people talking - redressing the power balance

Bloomsbury and Hampstead Community Health Councils recently collaborated with many local groups in Camden to plan a conference for older people in the borough. Initiated and organised under the Camden Healthy Cities Project umbrella, it aimed to give older people the opportunity to voice their concerns about services collectively, and to consequently inform the joint planning process. A further aim was to develop a user-led forum and to inform people more fully of services that exist.

Older people, together with local organisations from both the statutory and non-statutory sectors were involved with planning the conference. It was recognised by everyone involved that it was the beginning of a long process to involve users more fully in service planning. It proved to be a learning process for everyone, and demonstrated the value of working together rather than as isolated organisations.

The conference was organised under the principles of the World Health Organisation declaration *Health for All by the year 2000*:

- * A commitment to increasing community participation.
- * Developing working partnerships between different sectors and organisations.

- * Working to reduce inequalities in health.

The planning of the conference was extremely dynamic, and the original idea to hold a one day conference where older people could meet service managers was altered. It was felt that if an effective forum was to be created, people needed the opportunity to exchange ideas without managers being present, as the managers would possibly dominate the day.

Two separate events were planned: the first day was held in October 1991, with managers invited to a later meeting in December where the findings of the first day were presented. The CHCs organised information stalls, a workshop on information needs and an information pack, as well as being involved in the general conference planning.

Both conferences were well attended by people from all communities in Camden, including the Chinese, Bengali and Greek communities. Translation throughout both days was available, and was used by participants. A guiding aim was that the conferences should be enjoyable, rather than dull, as is often the case in traditional consultations. Multi-cultural food was available at lunch time, and there were presentations from various local organisations.

An important factor was that the conferences were held in a local community centre, rather than tucked away in the bowels of a Town Hall or Health Authority. The conference was widely publicised through posters, and there was extensive networking with local community workers.

The planning process was extremely informative, and demonstrated the complexity of developing user participation in planning, and how it is essentially a slow process. In tandem with developing user forums, there must be extensive campaigns to publicise services more effectively in a way that encourages healthy discussion about those services. The conference was the beginning of a dialogue, which attempted to break traditional divisions between services and between service users and providers. Most important of all, users were allowed to set the agenda and to have consultation at the start of planning.

Parallel to "Older people talking", Bloomsbury and Islington Health Authority were developing Care Group Commissioning Conferences, with the aim of informing purchasers for 1992-3 contracts.

Bloomsbury and Islington CHCs organised ten user representatives for the older peoples' conference, and held a pre-conference briefing. "Older people talking" had enabled many older people to find out more about services, and all the Bloomsbury representatives were drawn from this conference. The commissioning conferences were not felt to be the ideal way forward as they were organised hastily, but they proved to be a positive learning process for all involved.

User involvement in service planning is at a very early stage, particularly within the NHS. Both these conferences were a beginning, and should not be seen as ends in themselves, but part of an on-going process. In order to develop effective user participation, no body should be seen as the sole forum, and no process should be seen as exhaustive. Instead, a complex network of different organisations and people exists, a body of energy that can be used constructively by CHCs and health and local authorities.

Appendix :

Formal consultations - the GLACHC Code of Good Practice

It is clear from the foregoing pages that formal consultations are only the tip of the iceberg as far as user involvement is concerned. Clearly, there are many ways in which users should be involved as a continuous process. This principle is acknowledged in *Consultation and Involving the Consumer* (NHS Management Executive, 1991). However, there are still occasions when a Health Authority will need to consult on proposals for a major closure, substantial development or substantial variation of the service.

The GLACHC Code of Good Practice sets out some indicators of what is important to make a formal consultation meaningful. Following its publication, many London CHCs endorsed its contents, and it formed the basis of dialogue with a number of London District Health Authorities.

It should be read in conjunction with the relevant circulars, which set out the context within which CHCs operate.

The GLACHC Code of Practice is as follows:

1. Take consultation seriously

Health Authorities should have regard for the spirit of *Consultation and Involving the Consumer*, and should start from a presumption that it is a user's right to be consulted, and that the Health Authority will consult. That means, wherever possible, trying not to make "urgent" changes which avoid the need for consultation.

It also means that Health Authorities should interpret "substantial" in such a way that consultation is seen as the normal practice, to which only minor exceptions will be made.

In addition, consultation should be part of an on-going process of involving local users.

2. Consult widely

Consultation should take place with the CHC, and with a wide variety of community groups.

The CHC is extremely important, and has statutory responsibilities. It should be recognised that

community groups which are not primarily "health related", eg tenants' associations, luncheon clubs etc, are also important in the consultation process. Health Authorities should work with the local CHC and the Council for Voluntary Service (or equivalent) to draw up a list of groups to be involved with consultation. Lists of appropriate groups may vary according to the subject of consultation.

Health Authorities should also seek the views of individuals who may not be in organised groups.

Health Authorities must consult in clear language, free of jargon.

3. Advertise consultation widely

Health Authorities should widely advertise consultation in the local media, including ethnic media.

4. Give enough time

Adequate time should be given for the consultation, taking into account when the consultation is taking place, eg over holiday periods. The timetable of the consultation process, including information about when final decisions will be made, should be clearly stated from the beginning of the consultation.

5. Consult with all ethnic groups

Serious effort and commitment must be made to consult with the whole community in terms of race, culture, ethnicity and religion. This will mean a commitment to :

- * Translation of material for consultation, widely available from the start of the consultation procedure.
- * Sensitive language and illustrations in consultation material.
- * Serious regard for the calendar of festivals, holidays etc, of local populations in arranging consultation schedules.
- * Recognition that changes may impact differently on different parts of the community.

6. Consult with the whole age range of the community

Serious effort and commitment must be made to consult with the whole age range of the population. For example, this means that if meetings are held as

part of the consultation process, they must take place at a time suitable to both working and retired people, having regard for the preference of many older people not to go out at night.

7. Consult both women and men

Serious effort and commitment must be made to consult with women and men in the community. This means that consideration must be given to accessibility and acceptability of venues, the need for women speakers at meetings etc. Consideration must be given in each consultation as to how women can be enabled to participate fully.

8. Consult people with disabilities

Serious effort and commitment must be made to consult with people with disabilities in the community, for example:

- * Tape and braille versions of documents should be available from the start of the consultation period.
- * Large print summaries of documents should be available from the start of the consultation period.
- * There should be awareness of the need for clear material. eg good contrast of print and paper.
- * Signers should be available for consultation meetings.
- * Consultation meetings should be held at accessible venues.

9. Consult in a range of neighbourhoods

Serious effort and commitment must be made to consult with the community in all parts of the district concerned. This might mean taking meetings to different locations in the community.

10. State options for change

Health Authorities should be clear about the benefits and disadvantages which they envisage as a result of the proposed change. These alleged benefits and disadvantages should be compared with alleged benefits and disadvantages of other possible changes, as well as the benefits and disadvantages of making no changes.

11. Make financial information available

Health Authorities should provide adequate financial information to enable proper judgement to be exercised in the consultation process.

12. Be clear about implications for staff

Health Authorities should state the implications for staff of proposed changes.

13. Involve local authorities

Local authorities should be fully involved in consultation on matters affecting their local populations.

14. Publish the results of consultation

All responses to consultation should be collated into a brief summary document, giving details of the consultation procedures used, the groups involved and the comments received. It should establish a clear picture of the level of involvement in consultation and support or opposition to proposed changes.

15. Listen to what people say

Health Authorities must undertake that they will take into account the views of local individuals and groups in reaching decisions at the end of the consultation period.

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About GLACHC

The Greater London Association of Community Health Councils (GLACHC) is a voluntary association of CHCs in London. Its aims are as follows:

- * To provide information, training and support to Greater London Community Health Councils;
- * To help Greater London Community Health Councils acquire a higher public profile;
- * To provide a forum for users of the Health Service in London to express their views on the Health Service;
- * To promote co-operation and liaison between Greater London Community Health Councils, user groups and associated voluntary organisations.

GLACHC is a company limited by guarantee. Membership is open to all CHCs in Greater London. Other organisations, including voluntary organisations, user groups and non-London CHCs may become Associates of GLACHC.

For further information, please telephone the **GLACHC** office on **071-387 2171**.