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User Representation in the NHS and the Future of Community Health Councils

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DRAFT DISCUSSION PAPER:
Not for circulation or quotation

USER REPRESENTATION IN THE NHS AND THE FUTURE OF CHCs

by

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Foreword

This is a first draft of a King's Fund discussion paper on user representation in health care and the future of Community Health Councils. It is presented to participants at the 28 June 1990 workshop on 'User representation in the NHS' as a starting point for discussion of some of the issues raised for structures of user representation by the current reforms to health and social care.

The paper will be revised and expanded as a result of discussion at the meeting, prior to its publication by the King's Fund.

Introduction

This paper explores the issue of user representation in health care in the light of the important changes to the organisation and funding of health and social services outlined in the government's reform programme for the NHS and community care. It is a paradox that although the need to make services more responsive to individual users was ostensibly one of the principal reasons for embarking on the reform of health and community care, very little thought has been given to how user representation needs to be organised to meet the challenges of the new health and social care environment. Some of the reasons for this are touched on in this paper, which seeks to begin a wider discussion about the way in which users interests can be represented in the new world of health and social care providers and purchasers.

In doing so, it has proved difficult to separate general questions about how users should be represented within the new structures from questions about the future of Community Health Councils (CHCs). However, the future of CHCs is only one aspect of the much wider question of how users should be involved in the planning, monitoring and management of health and social care. Accordingly, the paper attempts to identify the fullest possible range of points at which users' interests should be represented in the new structure, at the same time as giving attention to the narrower question of the future of CHCs.

The paper's first section summarises the health and community care reforms themselves in an attempt to map the changing environment in which user representation will take place. The second sketches the history of 'consumerism' and user representation in the national health service in order to indicate the ideological and organisational context within which changes to user representation in health and social care must be considered. The third examines the strengths and weaknesses of CHCs in representing users' views on the organisation and delivery of health and community care. The final section takes a broad look at the new health and social care commissioning structures and indicates the points at which user involvement is needed. It then explores the future for user representation and suggest a possible avenue for the development of CHCs. The paper ends with a set of questions designed to structure debate within CHCs and other interested bodies on the way in which user involvement should be and organised within the new system.

1. The shape of reform

British health care is in transition. Moves to introduce an element of managed competition into the National Health Service are resulting in organisational and cultural changes of great complexity and with a wide range of implications. These changes were outlined in three government white papers: *Promoting Better Health*, *Working for Patients*, and *Caring for People*, and are embodied in the new contract for general practice and the National Health Service and Community Care Act 1990 (1). Currently, health and social services authorities are in a ferment of reorganisation aimed at having the new service structures broadly in place by April 1991.

The reforms to British health and community care are multifaceted, and have been amply summarised elsewhere (2,3). Central to them is the separation of responsibility for funding services from their provision. The intention is to turn health authorities and social services departments into discriminating purchasing agencies who seek to obtain the best care for their residents by buying services from a range of public, private and voluntary providers. GPs who hold practice budgets will act in a similar way for those services which they are eligible to provide or purchase. These will include elective surgery and a range of other routine treatments, procedures and tests. Other important aspects of the health service reforms include changes intended to make clinicians more accountable for their performance, and to streamline the management of the NHS.

Caring for People, the white paper on community care reform, designates local athorities as the lead agencies for funding and organising support for frail elderly people and those with physical disabilities, learning difficulties and long-term mental health problems. In parallel with *Working for Patients*, it stresses the role of social services authorities as purchasers of care from a range of providers in the public, private and voluntary sector. It outlines mechanisms intended to result in the improved management of cases and in services better tailored to individual need.

The government's stated intention in undertaking these major reforms was to address some of the perceived weaknesses of British health and social care. These include:

* a lack of responsiveness to service users;

* waiting lists for elective surgery in many parts of the country;

* poor and inappropriate services for the priority groups;

* indications that, in some places, resources could be more efficiently and effectively used.

While many uncertainties about the reforms remain, it is already clear that they will effect a redefinition of the boundaries between clinical treatment - which will remain the reponsibility of the NHS - and continuing care of people with disabilities - much of which will be organised and funded by local authorities. For health and social care agencies themselves, the reforms will involve a very significant internal restructuring in order to separate out "provider" functions, and create a new capacity for service specification and commissioning.

Potential and risks

The government's reform strategy is both ambitious and high risk.

The principle of redistributing purchasing power and creating an arm's length relationship between purchasers and providers is one with considerable ppotential for improving the type and quality of care available to users. At the same time, the introduction of competition may distort priorities for health and social care. This could happen if price incentives encourage hospitals to concentrate on providing services that are in demand by purchasers outside their locality at the expense of services needed by local people. It is also likely to become even more difficult to ensure an comprehensive, integrated approach to service delivery with multiple (and at times competing) providers.

This will pose particular problems in those many areas of support that cannot be neatly compartmentalised into 'health' and 'social' care - for example, services that support people with dementia and their carers. Here, there is considerable potential for acrimonious disputes about responsibility and for attempts to shunt costs between agencies.

Another risk is that GPs will respond to budgetary constraints by under-treating patients, providing inferior treatment, and/or refusing to admit certain potentially costly categories of patient onto their lists. In the community care arena there are allied concerns that budgets simply will not stretch to cover all those who need support, so that provision will be patchy, of poor quality and/or crisis-oriented.

For both health services and community care, much will depend on the overall funding made available by central government. The level of resourcing is, as yet, unknown. Continuing resource constraint is, however, a virtual certainty: tensions between the need to contain costs and to improve service quality underlie all three white papers. This tension will be clearly reflected on the ground as contracts are specified, costed, negotiated and monitored. Given this, the challenge will be to produce health and social care that is equitable, effective, efficient, accessible, appropriate and responsive.

Another global concern about the reforms centres on the competence of service purchasers. Health and social services managers have very limited experience of specifying and commissioning services. Traditionally, their work has concentrated on direct service managment. Assessing health needs and designing services to meet them has been as much a service provider responsibility as a management one. Indeed, in the NHS much of the information and expertise needed to do these things - and then to monitor service effectiveness - is probably located with health professionals who will find themselves on the provider side of the 'Chinese wall' which the Department of Health is urging health authorities to erect between their provider and their purchaser sides (4).

In any case, critical information and skill gaps will hinder the effectiveness of health services purchasers. For example, needs assessment skills on the public health side are widely acknowledged to be in very short supply. Quality measures are currently poorly developed in the health and social care fields, and are frequently difficult to interpret (4). Overall, information on health outcomes - an essential component of any thorough evaluation of health care effectiveness - remains primitive and extremely difficult to interpret.

As a result, there is a danger that price considerations will dominate the commissioning process, since effectiveness and other quality measures are so poorly developed. While it is clear that the first NHS service specifications and contracts will do little more than reflect existing patterns of provision, in the longer run there is a very real risk that quality measures, including measures of clinical effectiveness, will become subordinated to cost, which has the advantage of being easily measurable. Continuing resource constraint will, of course, increase the likelihood of this (5).

2. 'Consumerism' and representation in health and social care

'Consumerism'

The documents outlining the health and social care reforms have been strong on the rhetoric of increasing user responsiveness, but are very unclear about the actual mechanisms through which this is to be achieved. In particular, there is uncertainty about the extent to which user representation will be permitted within the new structures.

The notion that health and community care was insufficiently responsive to users gave impetus to the government's plans for restructuring the NHS and community care. This concern is a long-standing one which dates from the 1960s. It relates to more general anxieties that state welfare services like health, housing, and education were rigid, bureaucratic, and dominated by professional interests. By the end of the 1980s a commitment to 'consumerism' and putting users' interests first had become a focus for social policy nationally. The need to consider users' views was beginning to be reflected widely in planning and service rhetoric at local level (6).

Two different ideologies have contributed to this development. One was the broadly based growth of the post-war consumer movement, which was linked with efforts to improve citizen participation in local government and other public services. Much of this effort to involve or listen to users was aimed at making services more responsive. In many cases, it also centred on countering deprivation, disadvantage and discrimination (6).

In the 1960s and 1970s voluntary and other special interest organisations began to work to ensure that users' views were reflected in service design and delivery. In the health field these included the National Association for the Welfare of Children in Hospitals (NAWCH), MIND, MENCAP, the National Childbirth Trust (NCT), the Patients Association and others. Within the NHS, offical recognition of the need for some sort of a consumer voice came in 1974, when Community Health Councils were established to represent the views of local people to NHS management and to act as the 'patients' friend'.

The other, more recent, 'consumerist' influence in social policy is rooted in the market economy and the close-to-the-customer orientation of some sections of the business and commercial world. The need for the public sector to learn from the marketplace has been stressed by the Conservative government since it came to power in 1979, and this thinking has been extremely influential throughout the public sector (6,7). In particular, the idea of replacing welfare monopolies with a range of providers drawn from the public, private and voluntary sectors and of fostering consumer choice has been central to social policy changes during the 1980s. These ideas are, of course, reflected in the proposals for the reform of health and community care.

In theory, these two different strands of consumerism should be able to complement each other. In practice, market place models often sit uneasily with approaches to user involvement which emphasise collaboration and empowerment. This is partly because they tend to stress individual choice in health 'purchasing' and decision making, and fail to recognise collective interests and commonalities, and the need for representation they engender. In particular, business approaches - and the consumerist models derived from them - rarely centre on encouraging users to take an active part in designing and monitoring services. Instead, the emphasis is on collecting information from individual users in order to inform management decision making. Competition between suppliers and the capacity of the consumer to exercise choice between them is seen as the critical mechanism for promoting responsiveness.

In practice, models of consumerism based on the (usually retail) marketplace do not easily translate into the realities of large-scale welfare bureaucracies like the NHS, which are supported by general taxation and have equity and accessability as central tenets of the organisation. The key problem here is that users of health and social care services have no direct power to purchase services, and that there is often, in any case, little or no choice between service options. This situation will not change with the implementation of the health and social care reforms: most patient 'choices' will be predetermined by commissions established by health authorities, budget holding practices and social services departments. *Working for Patients*'s emphasis on market mechanisms stops well short of giving individuals direct purchasing power: instead, money will preceed patients, who will generally be obliged to abide by the purchasing decisions of commissioning agencies.

There are further reasons why individual decisions about health care do not mirror commercial transactions in the marketplace precisely (5). In particular, information that is essential to markets - for example, on price, effectiveness, and quality - is frequently absent in the health service. In addition, many people use health services infrequently, and for different reasons each time - a situation that makes comparisons between services more difficult. In practice, too, the type, timing and mix of health care is often "customised" for individuals, so that services are not fully comparable between cases.

User representation in the NHS

Klein has emphasised the tension between central and local accountability that has characterised the NHS since its inception (8). This was reflected in the muddled role of health authorities, which were expected to take responsibility for service management at the same time as representing the interests of local people (9). This confusion undoubtedly contributed to the ineffectiveness of some health authorities, and to the government's decision to reconstitute them along company board lines, with no explicit representative function. Although post-white paper health authorities will be drawn largely from local communities - and some commentators have argued the case for including "community directors" to represent local interests among their non-executive members - their role will be managerial, with clear lines of accountability for performance to Regional Health Authorities and, through them, the NHS Management Executive and ministers (8, 10).

As service purchasers, the new health authorities will be responsible for needs assessment and for monitoring user satisfaction and service quality. This means that health authorities could develop a distinctive purchasing role, in which they exert leverage on behalf of local communities as they commission health services (10). Theoretically, at least, this could make other forms of user representation unnecessary, with health authorities acting as advocates for local people.

The thrust of the white paper reforms means, however, that although health authorities will be accountable for their performance to Regions and - ultimately - to ministers, they will have no direct accountability to local people for the quality of their purchasing decisions. Klein has pointed out that:

> 'There is...no market to control the managers. If the manager of a supermarket chain fails to be sensitive to consumer needs the market will punish him or her. If the health authority fails to be sensitive to consumer needs there is no such mechanism' (8).

This situation seems likely to extend to budget-holding GP practices who will be responsible for purchasing certain patient services direct from providers, or for supplying them themselves. Although people will be able to change practitioner if they are unhappy with the services provided, it is, as yet, unclear whether they will have the access to alternative providers and information about services required to exercise effective market sanctions.

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Accordingly, purchaser monitoring will be needed because - for the reasons given above - the conditions of managed competition outlined in *Working for Patients* and *Caring for People* are unlikely to provide sufficient safeguards for users' interests on their own. The commissioning agencies will design service specifications and set contracts on users' behalf, but cost considerations will be important for them as well. Indeed, in conditions of continuing resource constraint, it is likely that meeting financial targets will continue to play a key role in assessments of health authority performance by RHAs and central government, especially considering the difficulty of developing adequate quality assessments of health care. Independent, local representation and monitoring on users' behalf will continue to be necessary to ensure that considerations of cost and quality are balanced in a way that benefits users. Health and Social Services Authorities' inexperience as purchasers, coupled with their lack of experience and skill in involving users in service design and monitoring, make this particularly important, especially in the short term.

It therefore seems likely that, in the absence of direct local accountability in the new health authorities, responsibility for representing community interests will fall even more squarely on CHCs when the new structures are in place (8). At the same time, the major responsibility for the organisation and monitoring of continuing support for people with disabilities - traditionally one of CHCs' major preoccupations - will fall outside the health service, and be taken up by local authority social services departments. With this in mind, the challenge must be to consider how the councils could be restructured to represent users' interests more effectively in the new environment.

3. The role of Community Health Councils

Community Health Councils (CHCs) were established in 1974 to represent user and community interests in the NHS. From the start, there was no clear mandate for them, and their representative function overlapped in important ways with that of health authorities. The statutory duties of CHCs were defined in broad terms: they are "to keep under review the operation of the health service in its district and to make recommendations for the improvement of that service" and to publish an annual report. Their remit includes a reponsibility for monitoring the effectiveness of collaboration between health and local authority services, which was extended to cover family practitioner services in 1985.

CHCs have rights to be consulted by the health authority on any substantial development or variation in service. They have a right to information about NHS services; to observer status at health authority meetings; to receive comments from the health authority on their annual reports; to an annual meeting with the health authority and Family Practitioner Committee (FPC); and to enter and inspect NHS premises (11).

Variation in performance

Within these broad guidelines, CHCs were left to interpret their role and their relationships with the health authorities and FPCs they related to for themselves. Over the years, little further guidance has been forthcoming from central government. Accordingly, there is wide variation in the way that CHCs interpret their role, and in their effectiveness. In addition, CHCs have tended to develop in isolation from each other, with surprisingly little cross-fertilisation of ideas or even agreement on what constitutes good practice (11, 12). This and their broad generic remit may have contributed to the fact that CHCs have not always been effective at linking up with special interest groups who may be concerned about health services - for example, with mental health service users groups, organisations of people with physical disabilites, local pensioners and mothers' groups and the like. In addition, the way that they interpret their responsibility to relate to the population whose needs they represent varies widely.

Within their very broad brief, different CHCs have chosen to concentrate on different areas. Responding to offical consultations and participating in HA planning; advocacy; complaints handling; identification of service gaps; service monitoring and health education and information are all legitimate areas for CHC involvement.

Long-standing problems

Apart from their variable quality, a number of other persistent problems with the organisation and accountability of CHCs have been identified during their sixteen year existence. One of these concerns accountability and representation.

Half of all CHC members are appointed by the local authority(ies) to which their District Health Authority relates. One third are elected by voluntary organisations, and the remainder are appointed by CHCs' establishing authority - that is, Regional Health Authorities in England and the Welsh Office in Wales. CHCs may also co-opt members to serve on working groups. The acccountability of CHC members is largely left up to individual voluntary organisations and local authorities to determine. In essence, the composition of CHC membership is a compromise between individual and group representation, and lines of accountability to local people are, accordingly, confused. In addition, concerns about the representativeness of CHC membership are longstanding: although there is little recent information on this, there has been continuing anxiety that ethnic minorities and groups from lower down the socio-economic scale are poorly represented.

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Another problem area involves the relationship between CHCs and their establishing authorities. RHAs in England and the Welsh Office in Wales have responsibility for membership appointments and elections; staffing and personnel issues; budgets and accounting and arbitrating between CHCs and DHAs. As CHCs' establishing bodies they have the power to attempt to influence CHCs' activities - a power which some CHCs consider that they have at times misused. Another potential source of conflict derives from the fact that CHC staff are employed by the establishing authority but are acccountable to members. Additional sources of conflict may arise as Regions begin to undertake the strategic role outlined for them in *Working for Patients*.

Resourcing

The average CHC has a budget of £35,000, from which it pays staff, rents, provides a service its population and services a council of between 18 to 24 members (12). CHC establishments vary markedly: they can be set as low as one half-time person, with a high of four full-time staff in a few places. Most CHCs have two full-time staff. CHC secretaries have generally been paid on NHS Administrative Scale 6, which currently attracts a basic salary range of between £ 11,962 and £13,994 a year, although Regional differences on pay are growing. No clear career development pathways are open to CHC staff within the NHS, and training opportunities have been poorly developed for them.

Overall, CHCs cost around £7 million a year to support, compared with a total NHS budget of around £20 billion. It seems clear that - given the extent of their remit and responsibilities - CHCs are under-resourced in both human and financial terms. This undoubtedly contributes to the variability of their performance. However, given this level of support and their unclear mandate, the range and bredth of CHCs' contribution to the NHS has been extensive, in terms of the support for innovation, user advocacy, and constructive criticism they have had to offer.

4. User representation in the reformed NHS: key issues

As the first section of this paper outlined, the NHS is currently undergoing a major transition, along with Local Authority Social Services departments. As structures change, and the new purchasers - or 'commissioners' as they are coming to be known - and providers of health and social care emerge and begin to function, it will be essential for new approaches to user representation to be developed.

The primary reason for securing user representation in service planning and commissioning, design and monitoring is to ensure that services genuinely encourage users to play the most active part possible in their own care, in accordance with the World Health Organisation's 'Health for All' principles. For the reasons outlined in the second section of this report, it will be insufficient to rely on the new health service commissioning bodies to do this job on thier own: an independent element, accountable in some way to local people is needed as well.

In representing the interests of service users within the new structures, it will be important for user representatives, contractors and service managers to be aware of the five dimensions which consumer theorists have identified as necessary to empower users and potential users of public services. These are: access, choice, information, redress of greivances and representation itself (13). Ensuring that each of these dimensions of empowerment is in place at every level of the new health and social care system will be a very considerable challenge.

Structuring user representation

In the new system, user representation will be needed in three main arenas. One is monitoring the effectiveness of health and social care planning and commissioning, with a focus on its success in meeting the health needs of the local population. Another involves the design of individual services. A third will centre on monitoring the quality and effectiveness of care. Figure 1 attempts to show key areas for user involvement in service planning, design and monitoring under the reformed health/social care system in diagrammatic form.

Developing effective user inputs in these three areas across the full range of health and social care commissioners amounts to a formidible brief. The fragmentation of purchaser and provider agencies is almost certain to make effective user representation harder. It is possible that - given expanded resources - CHCs might have the capacity to evolve and adapt to this multifaceted role which, in administrative terms, will need to span the new health and social care commissioning agencies - that is, health authorities, social services departments, the new Family Health Services Authorities (FHSAs), and budget-holding GP practices - as well as the full range of providers with whom they place contracts for care.

Realistically, however, it already seems likely that it will prove inappropriate and/or impossible for CHCs to operate in all these areas and to engage with the full range of commissioners and providers - especially given

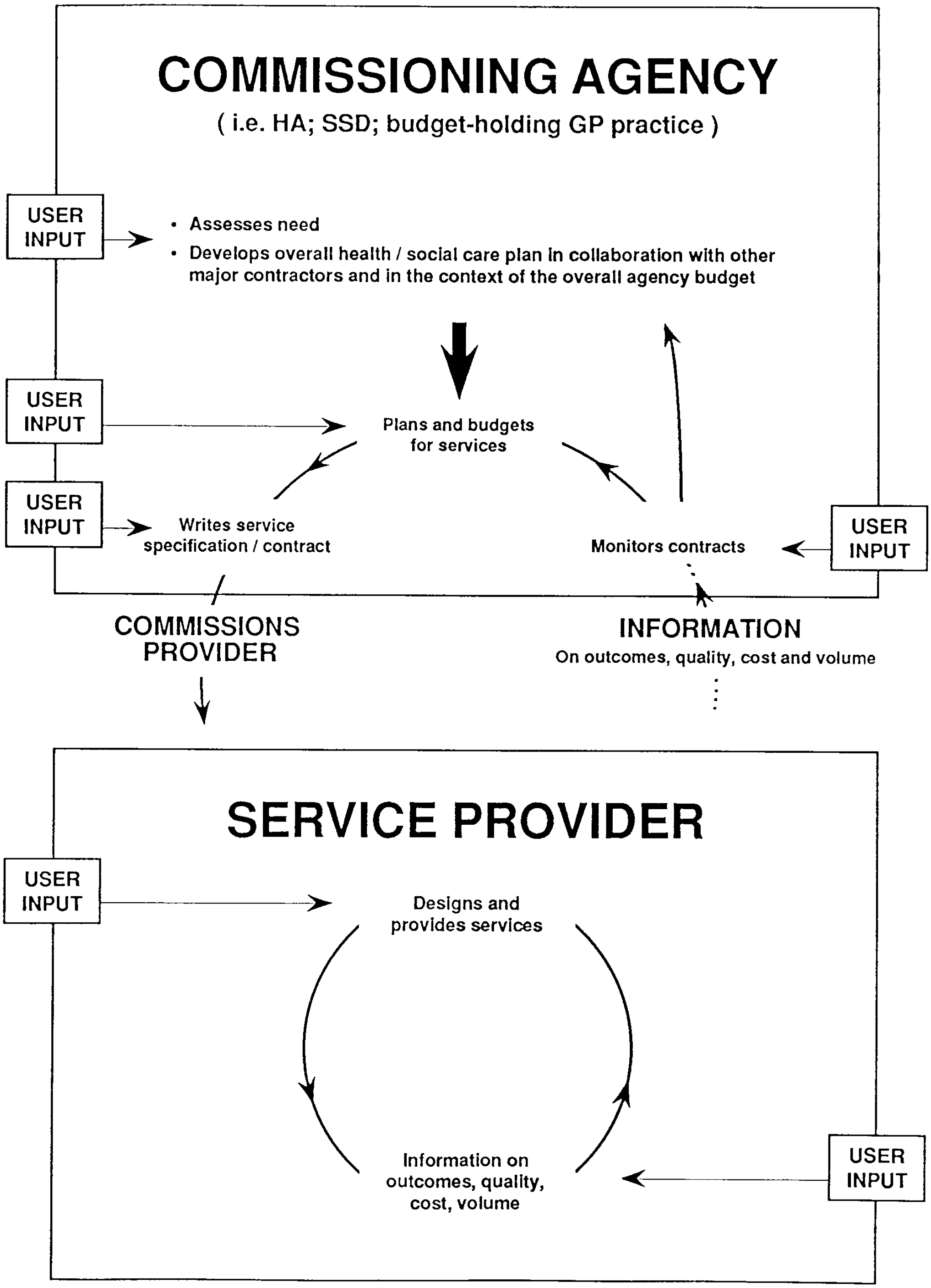

FIGURE 1: POTENTIAL AREAS FOR USER INVOLVEMENT IN THE REFORMED HEALTH AND SOCIAL CARE STRUCTURES

the resources likely to be available to them. In addition, shifts in agency boundaries are likely to create obstacles to CHC involvement in some areas. In particular, elected representatives in many local authorities are likely to question the appropriateness of CHC involvement in the design and monitoring of provision for priority group members. Another problem area is likely to be the extent to which CHCs will be permitted to monitor the service provision and commissioning of budget-holding GP practices and the services provided by family practitioners as a whole, although it is clear that independent scrutiny of their activity will be needed. A third will be self-governing NHS hospital Trusts (SGTs), where government have already indicated that they see CHCs' role as extremely limited.

In some areas, it seems clear that there will be alternatives to CHC scrutiny, although their effectiveness remains unproven. For example, in local authority-supported residential care the implementation of the health and social care reforms will involve setting new inspection mechanisms. Where these are locally based, and include strong independent lay representation, it may be that additional user input to service monitoring will be unnecessary. In others - for example, service design - it may be that a managerial commitment to solicit and monitor users' views will be sufficient, if its operation will then be subject to high calibre purchaser monitoring. All that is clear at the moment is that there is an urgent need to debate the form that user representation should take within the reformed health and social care system.

In doing so, it will be important for CHCs and other user representatives to be aware that monitoring service quality crucially involves assessing the effectiveness of clinical care. To date, 'consumerism' in the NHS - as construed by most managers and many CHCs - has concentrated narrowly on waiting times, the operation of appointments systems, the quality of the health care environment, amenities for patients and so on (13). While these are - and will remain - important areas for concern, the quality and effectiveness of clinical care is, in the end, the object of the exercise and independent scrutiny of it should be a focus for user representatives. [illegible]

Accordingly, if health and social care commissioning is to address needs appropriately in the future, it will be vitally important for user representatives to monitor medical and nursing care. This will mean increasing attention to a variety of outcome measures, as well as user involvement in medical and nursing audit, and ethics committees. that will be a welcome innovation

To sum up, key areas for CHC involvement in the reformed health and social care system appear to be:

* monitoring the effectiveness of services planning and commissioning in meeting the health needs of the local population; and

* monitoring the quality of service delivery, including the effectiveness of clinical care.

To carry out these functions effectively, CHCs will need to think critically about their links with the local community and user groups, and - where necessary - reforge them in a way that will encourage the widest possible user involvement in the design and monitoring of health services. Improved accountability for CHCs, and a clarification of their relationship with establishing bodies would contribute usefully to this process.

In restructuring the role of CHCs, it will be important not to lose sight of the need for other kinds of user involvement in health and social care (14). In particular, this should include the direct involvement of users and carers in the design of services across the health and social care spectrum (6). It will also be crucial to ensure that local authority funded support for the priority groups is subject to well-informed and independent scrutiny. Independent assessment of the adequacy of GP budget-holders' services will also be important - not least because achieving it is likely to prove problematic.

Key issues for CHCs

The final section of this paper raises some questions for CHCs to consider as they begin to debate their role within the reformed structures of health and social care.

1. What are the key features of the new health and social care environment? What would effective user representation within it look like?

2. What job should CHCs be doing within the new structures?

a. Which agencies should CHCs relate to in the new health and social care structures?

b. If there are areas where CHC involvement does not seem appropiate, how will users' interests be represented and protected?

c. Within each of the commissioning agencies, in which major areas (for example, service planning, design or monitoring) should CHCs aim to represent user views? How could this best be done?

c. What should CHCs' relationship to service providers be?

3. What resources and powers do CHCs need to do an effective job in the new structures?

a. Who should act as CHCs' establishing agency?

b. How should the relationship between CHCs and service commissioners and providers be defined? What powers should CHCs have within these new relationships

c. What order of human and financial resources will be needed to ensure that CHCs do an effective job?

d. What organisational supports (for example, at national and regional level) will be needed for CHCs?

4. <u>How should CHCs relate to their communities</u>?

5. <u>How should CHCs' effectiveness be monitored</u>?

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