

BACK FROM THE MARGINS

**WHICH FUTURE FOR COMMUNITY
HEALTH COUNCILS?**

DISCUSSION PAPER

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PREFACE

Scandals in long stay hospitals in the 1960s and 1970s led to the establishment of CHCs in 1974. CHCs were set up as public 'watchdogs'; as local committees of lay people with rights to visit hospitals and to be consulted by NHS managers.

Since then other arrangements for public scrutiny and protecting standards have been set up. NHS managers are increasingly encouraged to build up their own links with the community and to develop a more patient-centred service. Are CHCs, whose structure and terms of reference have changed little since 1974, still relevant?

CHCs have had a significant impact in changing attitudes within the NHS towards patients. Many activities now taken over by the health service were pioneered by local CHCs in the 1970s and 1980s. However, CHCs are not accountable for their actions or for their use of public funds and there are wide variations in the service they offer to the public and the NHS.

The NHS and Community Care Act has increased the remit and pressures on CHCs from health commissions, GPs, trusts and the public.

- ❖ There is now more scope for working in partnership with health authorities where their interests coincide with CHCs.
- ❖ Providers are developing their own patient and community initiatives and can use CHCs' expertise and networks.
- ❖ Primary care is increasingly important, but CHCs have no rights, little experience and no resources to work with general practices.
- ❖ Community care is not a part of CHC's remit, but many concerns for patients and carers are around the interaction between health and social care.
- ❖ Complaints have escalated – and dominate the work of staff in many CHCs.

However, at the same time some CHCs have been marginalised and are not taken seriously. They are under developed, under valued and, without doubt, under resourced for the role they are expected to play. The need for change is increasingly apparent.

To be credible with the public, and effective, a public 'watchdog' must

- ❖ Be **independent** of NHS management
- ❖ **Empower users** and reflect local people's concerns, based on local communities and covering both health and social care
- ❖ Be **effective** – with clear rights and responsibilities that can be enforced

- ❖ Be **accountable** for actions and use of funds, meeting agreed national and local standards
- ❖ Have **adequate resources** to carry out the duties expected of them.

Different options for developing the role of CHCs are discussed in this paper. On balance, the paper concludes that CHCs should be restructured as community based agencies that facilitate user involvement in the NHS and are accountable to the community. This would involve changes in the terms of reference of CHCs, additional rights and responsibilities and changes in the way members are appointed.

This paper is not a blueprint for action. It does not necessarily represent the views of either of our organisations, but we hope that it does provide a contribution to a discussion now taking place around the future of CHCs.

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INTRODUCTION

Scandals surrounding the abuse and neglect of patients in long stay mental hospitals led to the establishment of community health councils (CHCs) in England and Wales and local health councils in Scotland in the 1970s. Politicians and public were shocked to find that managers and professionals had not always protected vulnerable patients in their care. CHCs were set up as a committee of lay people with rights to visit hospitals and be consulted by NHS managers. Their purpose was to safeguard patients through more public involvement and scrutiny.

The scandals in the NHS are different now. They are more likely to be about financial dealings or the neglect of people with mental health problems in the community. There are now other bodies to audit standards. Are CHCs, whose structure and terms of reference have changed little since 1974, still relevant?

THE PAST

1 The beginning

Setting up CHCs

Community health councils were set up in 1974 to provide some public input into the planning, management and monitoring of the NHS. The initial idea came from the Conservative Government and was adapted by the incoming Labour administration and included in the 1974 reorganisation. Local health councils were set up in Scotland at the same time and local health and social services councils were established in Northern Ireland in 1991.

Most CHCs were made up of about 24-30 members, half of whom came from local authorities, a third were elected by voluntary organisations and the remainder appointed by regional health authorities (RHAs). The right to appoint half the members was given to local authorities to compensate for the transfer of community health services to the NHS from local authorities.

Regional health authorities were the establishing authority for CHCs (the Welsh Health Common Services Authority in Wales, Scottish Office in Scotland and Department of Health and Social Services in Northern Ireland). The establishing authorities were responsible for appointing members, employing staff, setting budgets, training and reviewing performance.

Role, rights and duties

As statutory bodies, CHCs have certain rights in relation to **health authorities** as well as some duties. These are outlined in Box 1.

There was little guidance either to managers or CHCs on how these rights should operate and there have often been disputes between local NHS managers and CHCs about their interpretation. In practice, if managers did not recognise them, the rights were unenforceable except by law. On occasion legal action to enforce consultation rights about hospital closures has been taken on behalf of CHCs by some local authorities.

Box 1
Rights and Duties: CHCs and Health Authorities

The CHC has the right...	
To information from Health Authorities.	<p>Excluding confidential information about individual patients or personnel information about individual staff.</p> <p>A health authority can appeal to the RHA if it considers that the CHC should not have access to information. Any disputes must be referred to the Secretary of State.</p>
To be consulted by Health Authorities on proposals for any substantial variation in use or development of the health services in their district.	<p>Including when changes are the result of a decision by an NHS trust.</p> <p>If the CHC opposes a closure, it will be referred to the RHA and if the RHA supports the health authority, the Secretary of State makes a final decision.</p> <p>There have been disputes about what constitutes a 'substantial' change of use.</p>
To enter and inspect health service premises in their 'home' district where NHS services are provided under contractual agreements.	This includes premises managed by the DHA, FHSA , local NHS trusts or private facilities where NHS patients are. But excludes GP surgeries (unless owned by the NHS).
To send observers to public meetings of the DHA and FHSA.	Local agreements decide whether the CHC observer is allowed to speak and stay for the private parts of meetings.
To meet formally at least annually with the DHA and the FHSA to which they relate.	
The CHC has a duty...	
To publish an annual report to the RHA on the performance of its functions.	Copies of the report must be brought to the attention of the public and provided to the DHA and the FHSA who must reply and must make their comments public.
The CHC is expected...	
To produce an annual plan (introduced in 1994)	RHAs are expected to discuss with CHCs the progress of their annual plans and the use they make of their resources.

2 Activities of CHCs

Core tasks

CHCs have identified five 'core' tasks, out of their broad remit of 'representing the interests of the local community'.¹

- ❖ Acting as a local voice for the community
- ❖ Acting as a watchdog for the community by monitoring local services
- ❖ Helping local people and local groups put forward their views to local NHS managers, in particular seeking out people whose views are not normally represented and acting as an advocate for them
- ❖ Providing information and advice to people who phone, write or come to the office
- ❖ Assisting people to make complaints.

National standards have been developed by ACHCEW on these areas for local CHCs to adopt, according to their local priorities.² However, they are not all statutory responsibilities. For example, complaints work is not a statutory requirement, in spite of the support for CHCs' role in complaints from the Department of Health and the Wilson Report.³

CHCs locally

Within these core tasks, individual CHCs have interpreted their roles differently. The primary role that the CHC chooses affects the way it works with local people and relates to NHS management. Different 'types' of working among CHCs are identified in Box 2.

- ❖ Some CHCs work closely with health authorities, while others do not. Some have extensive visiting programmes, undertaking over 50 visits a year. Others do only a few visits.
- ❖ Some CHCs work closely with voluntary organisations and involve local people in particular areas as co-opted members.

The freedom that CHCs have had in the way they work has led to innovation. But it has also led to variations between the services provided by CHCs. As a result a member of the public seeking information or assistance in making a complaint may get different services in one CHC than another.

CHCs have varied in the impact that they have had on local services. CHCs are limited in what they do and how they do it by the staff establishment and resources available to them. CHC members and staff also vary in skill, experience and commitment. Many factors outside their control also contribute to their 'effectiveness', such as the financial situation of the local trusts and commission, the attitude of NHS staff and their willingness to work with the CHC.

Box 2

Types of CHCs

Recent research identified five different models of CHCs that may overlap or change over time.

Independent challengers – CHCs that saw themselves on the 'side' of the consumer working for collective consumer rights, challenging the government but not working closely with the DHA and excluded from decision making.

DHA partners – CHCs that worked closely with the DHA and were involved in decision making. They were more likely than other 'types' to 'sell' DHA/FHSA plans to the public. Though concerned with individual consumer complaints, they did not always take the 'side' of the consumer.

Independent arbiters – CHCs that saw their primary role as an independent arbiter between consumers and the DHA and not taking the side of either. They did not see their primary role as being one of pursuing consumer complaints nor did they feel that they were necessarily on the side of the consumer.

Patient's friend – CHCs that worked for individual consumers rather than consumer rights in general and were particularly concerned with individual complaints. They were not closely involved with the DHA and were excluded from decision making. They saw themselves on the 'side' of the consumer acting as an arbiter between consumers and the DHA.

Consumer advocate – CHCs that were actively working for consumers' rights but using existing structures. They appreciated the importance of working with the health authority and were involved to a certain extent in decision making. They were more likely than any other of the types to see themselves as being on the consumers' side.

Buckland, S, Lupton C & Moon G, 1995, *An evaluation of the role and impact of community health councils. Social Services Research and Information Unit, University of Portsmouth*

3 Accountability

It has never been clear to whom CHCs are accountable or even to whom members of the public should complain if they are not satisfied with the service provided by the CHC.

CHC members

CHC members are responsible for overall policies and priorities, but are accountable to no one. They are not accountable to their appointing body. If they were, half of the CHC members would be accountable to the local authority and one sixth to the regional health authority.

The independence of the CHC may be undermined where local authorities appoint councillors or give all their places to nominees from the majority political party. They may expect their nominees to represent their views on the CHC.

The chief officer

As an employer the CHC is a hybrid. The chief officer is employed by the establishing body (the RHA in England) but accountable to CHC members through the chair on a daily basis. Many chairs have no experience of managing staff and chief officers may work during their CHC career with many chairs, who see their role quite differently.

Many of the working conditions of CHC staff are more like those of people working in the voluntary sector than the NHS. These include isolation, lack of support, the range of tasks undertaken and the tensions where paid staff work alongside an unpaid committee. Like the voluntary sector, there is no career progression for CHC chief officers.

The development of individual performance review for CHC chief officers has highlighted problems about how their performance is assessed, by whom and how far the officer's performance can be separated from that of the CHC as a whole. This raises the question of whether, if CHC chief officers are employed and paid by RHAs, they can be really independent.

Regional health authorities

In 1974 the regional health authorities were seen as distant enough from districts to be the establishing body of CHCs without interfering with their work. In practice there have been problems.

- ❖ Some RHAs have tried to restrict the activities of CHCs, both by direct intervention in their activities or in the appointment of staff.⁴
- ❖ There are wide discrepancies in the staff establishment, premises used and discretionary funds available.

CHC members and staff work in such a different culture from the NHS, it is difficult for RHA staff to understand and offer appropriate training and support. Perhaps the more successful regional work with CHCs has been where a former CHC officer has been given responsibility for working with them.

4 CHC resources

CHCs were set up mostly with two staff and an office – often in the early days in a hospital.

In 1974 the number and grades of staff, the budget and location of the office were all decided by the regional health authority. In most CHCs the establishment is still 2-3 full time equivalent staff. Since 1990 some regions have given additional staff to CHCs for specific tasks such as dealing with complaints or undertaking research. Many CHCs also employ staff on short term projects with specific project funding.

A small isolated office can also have problems in developing and maintaining a work programme. Where there are only two or three people staff sickness, holidays, poor performance or personal conflicts can have a very disruptive effect on all the work.

As a result CHC staff are working under considerable pressure, with increasing expectations and demands. Many are doing very high levels of overtime.⁵ A recent study estimated that a CHC requires a minimum of 3 full time staff to run the office and fulfil statutory functions, regardless of local factors.⁶ Developing community links, involvement in localities, liaison with GPs and community care, surveys, publicising the CHC, as required by the NHS Executive in EL (94)4, are not included in this estimate.

CHC members are also an important resource of the CHC – maintaining links with local groups, representing the CHC on committees and carrying out visits. However, since 1974 the number of CHC members on each CHC has been reduced, though this was opposed by CHCs. A CHC covering an area with a population of 100,000 may have the same number of members as a CHC covering a population of 500,000. CHCs in rural areas with scattered populations have particular difficulties. Health issues may be localised and the travel required between parts of the district for CHC members and staff are enormous.

The reduction in numbers seems to be the result of a confusion by the Government on the purpose of CHC members. For effective management or for making decisions, fewer members may be better, but for a council concerned with developing local networks and monitoring local services members need to be drawn from all over the districts and many communities to increase the involvement of local people.

Conclusions

CHCs have had a significant impact in changing attitudes in the NHS towards patients. Many activities now undertaken by the health service were pioneered by CHCs in the 1970s and 1980s. For example:

- ❖ Advocacy schemes for people in health care
- ❖ Support for local self help groups and community networks
- ❖ Surveys on users' views – now called quality assurance
- ❖ Research of unmet needs of some groups in the community – now called 'needs assessment'
- ❖ Health information services, providing information leaflets on services and rights
- ❖ Patients' charters, publishing standards and promoting patients' and carers' rights

It is easy to look at an individual CHC and find it wanting in relation to a particular 'core' task. No CHC can perform all the tasks to the same standard. Some are good at visiting, some excellent at representing complainants or at developing community initiatives. None – given the very limited resources available to them – can be good at all of them. It is easy to highlight the deficiencies in individual CHCs and for

managers to have a vision of a 'gold' standard for CHCs. This 'gold' standard cannot be achieved within current resources.

In 1994-95 the cost of CHCs in England and Wales was £16.24 million (£15.14 in England and £1.1 million in Wales).⁷ The average cost of a CHC in England was £82,300. In considering 'value-for-money', these costs need to be put in the context of local and national expenditure on patient and quality initiatives and health information lines. There is no information about this expenditure within districts, but money spent on national initiatives is considerable. Some examples illustrate this:

- ❖ The production of the league tables on hospital performance cost £500,000⁸.
- ❖ The national Patient's Charter help-line cost £1.49 million in 1992-93 and £1.84 million in 1993-94.⁹
- ❖ Pamphlets and brochures from the NHS Executive to managers on patient-focused issues for 6 months from October 1993 to March 1994 cost £423,000.¹⁰

In this context, the contribution of CHCs in involving local people and opening up the NHS to public scrutiny represents good value for money.

THE PRESENT

5 CHCs and the 'new' NHS

It is remarkable that CHCs have survived so long. Since their heyday in the 1970s, there have been several attempts to abolish them.

- ❖ In 1980 – the Government suggested that they were no longer necessary, as the abolition of area health authorities meant that the smaller district health authorities could be in touch with the local community directly.
- ❖ With the introduction of general management in the mid 1980s, some felt that good management would make CHCs unnecessary and managers would be able to represent patients' interests.
- ❖ In 1990, with the split between purchasing and providing services, some felt health commissions could become the 'champions of the people', unfettered by the responsibility for directly providing services. Subsequent 'collusion' between purchasers and providers has shown that this is not the case.

The changes in the NHS and Community Care Act recognised that the interests of those who purchase and those who provide services are different. Equally the interests of those using a service are different again. As was recognised in 1974 – representation and management are very different functions that require different skills.

The changes in the NHS that have occurred in recent years have brought a growing interest and investment in developing patients' rights and involving the community. National initiatives such as the Patient's Charter have been particularly influential. But at the same time there has been a weakening of the rights of CHCs. For example, the rights given to them in 1974 in relation to health authorities have not been extended to trusts, general practice or community care. The impact of recent changes is summarised in Box 3.

Box 3

The erosion of the rights of CHCs

- ❖ *Information:* CHCs have a right to information from health authorities, but not directly from trusts or GPs. This seriously limits public scrutiny of decisions on the use of public funds.
- ❖ *Consultation:* Formal consultation rights of CHCs about hospital closures and developments are less relevant than they were in the 1970s and 1980s. The health authority is responsible for consulting on the changes proposed by trusts, even though they are not directly responsible for these decisions. Today CHCs need to be involved early in the purchasing plan and before contracts are set in order to have an impact on local services.
- ❖ *Visiting rights:* CHCs have rights to visit NHS trusts, but more and more NHS care is provided in GP surgeries and by the private sector.
- ❖ *Observers on statutory bodies:* CHCs no longer have the right to speak as an observer at meetings of health authorities. They can attend as members of the public and speak if asked. They have no right to attend trust board meetings. Relationships are at the discretion of the health authority and trust, though in many districts close links have continued. With the abolition of RHAs, regional meetings may no longer be held in public.
- ❖ *Annual meetings with health authorities:* Most CHC officers and members have regular meetings with health authorities and so the formal annual meeting is increasingly seen as unnecessary.
- ❖ *CHC annual reports:* Most CHCs use the annual report as a way of communicating with the public rather than the health authority and so the right to receive comments from the health authority is less relevant.

6 Partnership with purchasers

The Government has made it clear that CHCs' main link is with purchasers. There are many areas where CHCs can work closely with purchasers – in particular in agreeing about the problems with current services, needs assessment and developing and monitoring quality standards in contracts. Differences are likely in addressing the needs assessed and the problems identified. This leads directly to the complex issues surrounding prioritising and rationing where there are no 'right' answers.

In addition there is likely to be increasing duplication between the work of health authorities and CHCs as health authorities become more involved in community based needs assessment, monitoring services and providing health information. Greater clarity around the respective roles of health authorities and CHCs will become increasingly necessary.

Some current examples of joint working between CHCs and health authorities are given in Box 4.

Community based needs assessment

Many health commissions are using CHC networks and contracting CHCs and voluntary groups to carry out surveys or consultations on their behalf.

Other health commissions are doing their own development work with the local community. They may feel that, with their much greater resources, they have better 'intelligence' from the grass roots than CHC staff and members.¹¹ There are, however, good reasons for health authorities not undertaking community networking themselves, but rather through the CHC or voluntary groups. These include:

- ❖ Health authorities and trusts are not seen by the public as independent and therefore what they say may be treated with suspicion.
- ❖ Community/liaison workers based in authorities and trusts are often fairly junior and have little power to ensure that attention is paid to unpopular messages. This may lead to disillusionment with the health authority or trust within their local community.
- ❖ Employees of health authorities or trusts cannot act as advocates against the health authority's or trust's decisions or policies.

Contract setting and monitoring

Health authorities are now responsible for monitoring contracts. In many CHCs the main activity was, and in some cases still is, visiting health service premises. Where visits are the main activity of members, the focus of the CHC may be on health services and providers rather than on taking a broader look at health issues, involving local people and seeking their views.

Visiting is important, both to familiarise CHC members with local services and to monitor services. CHCs can provide external validation to health authority monitoring. But CHC visits need to focus on particular issues, perhaps in response to any problems identified by users, using a 'dipstick' approach. They should not duplicate the work of the health authority.

Health information services

Regional health information services were set up in 1992. The service provided has varied between regions. Health authorities also set up local services. Interestingly some have contracted this task to the local CHC. More often they have set up a separate service which may employ the same number of staff as the CHC to undertake a small aspect of CHC staffs' work.

This is in many ways a disappointing development. Often it is important that the advice is given by someone who is independent of the service. In addition information helplines may seem to duplicate the service provided by CHCs. Many

helplines refer on enquiries to CHCs and CHCs report that the overall number of enquiries they receive has not decreased and for some CHCs has increased following the establishment of helplines.¹²

From April 1996 health authorities are responsible for providing the regional service through the existing freephone number. The requirements for the service from April 1996 outlined in NHS Executive HSG (95)44 go beyond the services now provided by most health information services including: contracts, services commissioning authorities and GP fundholders have purchased, diseases and conditions and treatments, including alternative and complementary therapies, outcomes and effectiveness data, maintaining and improving health and health issues of national and local interest.

The issue of who runs these information helplines deserves further attention. Providing such information services will require considerable investment. Since the purpose of the service is to inform and empower local people, it is essential that health authorities work closely with CHCs to ensure an effective use of resources and a high quality service.

Box 4 – Community initiatives and health authorities

Needs assessment

- ❖ A qualitative health needs assessment project, based at the Kings Cross Neighbourhood Centre, developed from proposals put forward by the CHC and Camden Healthy Cities (Bloomsbury CHC).

Developing community involvement

- ❖ Avon Health funded the CHC for a two year project to involve a wider range of people in health policy issues, develop district wide consultation networks, increase purchasers' knowledge of health needs and enable the CHC to respond more effectively (Bristol and District CHC).
- ❖ Two locality forums are being set up by a full time staff member based in the CHC with funding from the Health Authority and RHA (Rotherham CHC).

Surveys and contract monitoring

- ❖ Action research project was carried out with the DHA seeking views of elderly people in nursing and residential homes, especially with mental health problems. As a result five volunteer projects for elderly people have been developed (North Derbyshire CHC).
- ❖ Research was undertaken on how the care plan approach was working for mental health service users, interviewing users about the development of care plans and contact with key workers (Airedale and North Derbyshire CHCs).

Health information

- ❖ In Hillingdon the one-stop health shop is staffed by 2 health authority staff with a CHC bilingual outreach worker funded by the health authority and social services (Hillingdon CHC).
- ❖ In Luton and Stoke on Trent the health service help-line is based in the CHC office and managed on a day to day basis by the CHC chief officer (South Bedfordshire and N Staffordshire CHCs).
- ❖ Bilingual health information cards have been produced with information in Urdu and English. Twelve cards have been produced, for example on the services of GPs, dentists, opticians and A&E services (Rotherham CHC).

7 Relationships with trusts

Though CHCs' statutory rights now relate to purchasers, CHCs have traditionally had strong links with the providers in their district. The Patient's Charter provides a direct 'contract' between patients and providers, and trusts are now also developing closer links with their 'customers'. Some trusts employ patient representatives to deal with problems, enquiries and complaints. Quality monitoring increasingly includes patient satisfaction surveys and group discussions.

CHCs are reluctant to lose their links with providers. However, each CHC may have three trusts, though some have up to seven.¹³ This stretches the resources of the CHC. Reducing links with trusts would mean a major change in some CHCs in what members do, such as hospital visits. It would also mean that they lost contacts that fed into their work in developing policy and improving standards.

Many trusts are also unwilling to loosen their links with CHCs. CHCs have experience and expertise that can be useful to trusts. Many CHCs have also had long established representation on committees, such as maternity services liaison, quality, complaints, audit, consumer information and research ethics. Many NHS trusts want their help and the credibility with the community that CHCs may bring in developing user/ patient panels and in conducting consultations with the community. Current examples of joint working with trusts are given in Box 5.

Advocacy schemes are also becoming increasingly important for patients who feel unable to express their views or feel that their views are not being heard. To have credibility advocacy schemes need to be based outside service providers. They are often based within CHCs or other community groups.

Box 5

Initiatives with trusts

Developing services

- ❖ A Saturday service for young people was set up with Premier Health Trust at the CHC office in the town centre for young people on sexual health. Now separate premises for a young people's service have been found (SE Staffordshire CHC).

Audit and surveys

- ❖ A consumer audit project on acute and community health services and services for elderly people was undertaken with the College of Health (S Bedfordshire CHC).
- ❖ CHC members are trained to carry out quality audits for trusts and health authorities as part of Patient's Charter monitoring arrangements. Training for members is funded by the Airedale NHS Trust (Airedale CHC).

8 Complaints and the patient's charter

The Patient's Charter has raised expectations at the same time as services are undergoing major change. Complaints have a high profile in the Charter and numbers are increasing.¹⁴ The Wilson report recognises the role of CHCs and the importance of independent advice for complainants.

This has major implications for CHC staff and the workload of CHCs. Most CHCs give priority to members of the public who ask for help. Complainants in particular may be distressed and a prompt and sensitive response is important. A complainant or member of the public asking for help is an immediate priority and the work involved cannot be predicted.

CHCs have difficulty in maintaining even basic services with present staff establishments. CHC staff need to be out of the office to attend meetings, make visits or see complainants. However, this conflicts with the need to provide an information and advice service to the public. For safety reasons staff should not be alone in an office open to public callers, but inevitably this often happens where there only two staff.

Box 6

CHCs and complaints

- ❖ The CHC carried out a comparative study of the complaints procedures used in the district. Following the report of the NHS Complaints Review the CHC convened a joint complaints working party with representatives of four trusts, the DHA, FHSA and social services department. The group is developing common standards, joint training and arrangements for joint responses and investigations where a complaint involves more than one service (Salford CHC).
- ❖ In 1992 the closure of Winterton Hospital, a long stay mental hospital, was announced. Patients were to be transferred to the community over five years. The CHC and the hospital developed a proposal for an advocacy scheme for patients which is funded by six health authorities whose residents were in the hospital. The CHC chief officer is the line manager for the co-ordinator and staff who are employed by the RHA. As a result of the advocacy scheme a patients' council has been established which has monthly meeting with the trust board. It is hoped that the service will continue after the closure of the hospital in 1997 as a community mental health advocacy scheme funded by health and social services (South West Durham CHC).
- ❖ In Bradford the CHC runs an advocacy service for people with learning difficulties and older people. The service was set up in 1992 and two advocates help individual clients, works with groups and undertake training sessions (Bradford CHC).

9 Primary care

Primary care, not hospital care, will be the focus for services in the future. Primary care is a network of services commissioned and provided by NHS trusts, local authorities, general practitioners and health authorities, each with different arrangements for user involvement. There are no co-ordinated structures for user involvement and no clear vision of how users might best be involved in primary care, especially in general practice.

CHCs have been excluded from primary care so far, though most feel that it is a priority to become involved in this area.¹⁵ The reasons why closer working relationships have not developed, especially between GPs and CHCs include:

- ❖ CHCs do not have any legal rights in relation to general practice. They cannot require information, insist on visiting or on being consulted.
- ❖ GPs see CHCs mainly as assisting complainants against them and find it difficult to see the CHC in other roles.
- ❖ CHCs focus on the community, whereas GPs focus on the individual patient. Not everyone is registered with a GP, particularly in inner city areas.

Arrangements for consulting patients based solely on practices cannot reflect the views of the whole community.

- ❖ The pressures of time and work on GP staff and CHCs.

The lack of public scrutiny and involvement in decisions of GPs is a major issue which needs to be addressed, particularly as there is a growing gap between the best and worst primary care services. But there are no easy answers:

- ❖ GPs are currently independent contractors and not all welcome CHC or public scrutiny.
- ❖ The patient-doctor relationship is a personal and often long term one – and many patients who participate may not be able to take a broad look or be questioning or critical. They may also support practice policies that are undesirable – perhaps wishing to exclude patients with whom they do not want to share the waiting room – drug users, people who are mentally ill or the homeless.
- ❖ GP practices tend to cover small populations and the resources needed to develop local involvement could be substantial.

Some current examples of joint working with primary care are given in Box 7.

Box 7

CHCs and primary care

- ❖ A researcher is funded by the DHA and FHSA to work with GP practices to undertake a rapid appraisal of the locality, followed up by in-depth qualitative research on a particular topic (such as maternity services or young people's health). So far surveys have been carried out in three practices (Montgomery CHC).
- ❖ Advice and assistance was given to single-handed practices in designing and carrying out a patient satisfaction survey (S E Staffordshire CHC).
- ❖ Consultation to find out what patients thought about a proposed move of the practice to new, but less central, premises, was undertaken by the CHC (S E Staffordshire CHC).
- ❖ A survey of the primary care needs for black and ethnic minority women and their children was undertaken with funding from the health authority and the London Primary Care Development Initiative (Greenwich CHC).

10 Community care

Local authority services are also outside the remit of CHCs. However, CHCs deal with many people receiving both health and social care and the problems caused by

the gap between them. The division between health and social care makes no sense to the public and CHCs have little credibility if they ignore this.

The introduction of community care also means that some people whom the CHC once had a statutory responsibility to represent are now receiving services provided by the local authority, private or voluntary sector. These people are often the most vulnerable clients and there is no agency equivalent to the CHC to look after their interests.

Though CHCs' remit does not strictly cover these services, most CHCs have felt that they must retain some responsibility in monitoring the implementation of community care.¹⁶ The guidance from the NHS Executive recognises this dilemma and recommends that CHCs and local authority social service departments agree the part that CHCs '*can play in the joint health and social services arrangements such as hospital discharge arrangements, advocacy associated with complaints, feedback from users and the CHC contribution to community care plans*'.¹⁷

Apart from not having additional resources for this, there is another problem. CHCs are not independent from local authorities, in the same way that they are from the health service. Half the members of CHCs are appointed by local authorities who are responsible for community care and a third from voluntary organisations, some of whom may be providing community care.

Box 8 **CHCs and community care**

- ❖ Surveys have been carried out by CHCs asking GPs about their experiences of the implementation of community care. In South Warwickshire access to social workers and psychology services were highlighted as major problems. In Manchester GPs found the home help service was the hardest to access and they needed more information on the voluntary sector (South Warwickshire and Manchester CHCs).
- ❖ HealthLINK started out as a project to help people in Camden who had difficulty getting out and about to use CHC services. An active network of service users is being established to help house-bound people identify their concerns and say what improvements they would like to see. A development worker is employed by the CHC for three years with Joint Finance (Bloomsbury CHC).
- ❖ A survey of users' views on care management, assessment, and outcome was commissioned by DHA, FHSA and the Social Services Department (Oxfordshire CHC).
- ❖ The Action on Health and Community Care Forum was launched in Liverpool with local community groups, especially for ethnic minorities (Liverpool Central and Southern).

Conclusions

CHCs have survived for over 20 years, while revolutions in health care have gone on around them. For years CHCs have been calling for a review of their role and functions.¹⁸ A review of their role promised by the Department of Health for 1985 never happened.¹⁹ How much longer can a review be deferred?

A major problem in evaluating the work of CHCs is the result of the wide remit and lack of guidance that CHCs have faced from the start. The enormous variations in what CHCs do and in what they are trying to achieve within limited resources makes comparisons difficult. Factors affecting the performance of CHCs that need to be taken into account in any future review are outlined in Box 9.

All the changes since the NHS and Community Care Act 1990 have increased the remit and pressures on CHCs from health commissions, GPs, trusts and the public. In many areas, CHCs have not been given additional resources to deal with the increased work. Pressures on CHCs are very great and changes are long overdue to help them become more effective and to bring them out from the margins into the centre of the health system.

Box 9 Strengths and weaknesses of CHCs		
Factors affecting CHC performance	Strengths	Weakness
Lack of guidance/standards for CHCs	Flexibility and responsiveness to local needs Scope to develop new activities	Different services provided to public and NHS by even neighbouring CHCs Lack of focus in activities, try to do too much Problems of enforcement on voluntary council
Lack of enforceable rights for CHCs	'Managers can get on and manage'	'Watchdogs without teeth' Disputes with NHS about procedural rather than substantive issues Effectiveness depends on co-operation of management
Method of appointment of members	Members drawn from many different groups Strong local authority links	Absentee members – and no sanctions Appointments of members on political affiliation No accountability
No line of accountability	Independent of NHS	No external audit or means of calling CHC to account
Resources	Resources not dependent on managers' perception of a 'good' CHC	Resources limited and do not reflect activities or quality of work

THE FUTURE

11 A framework for community involvement

Change is needed. There are a number of options for the future. Whatever route is chosen, this must build on the experiences gained from 20 years of CHCs.

Experience from CHCs demonstrates that to be credible with the public and effective, a public 'watchdog' must

- ❖ Be **independent** of NHS management
- ❖ **Empower users** and reflect local people's concerns, based on local communities and covering both health and social care
- ❖ Be **effective** with clear rights and responsibilities that can be enforced
- ❖ Be **accountable** for actions and use of funds, meeting agreed national and local standards
- ❖ Have **adequate resources** to carry out the duties expected.

Independence

The arrangements for community involvement must be **independent** of those for managing, purchasing or providing services.

In 1996 the Regional Offices of the NHS Executive will replace RHAs as the establishing body for CHCs. This may jeopardise the independence of CHCs since the NHS Executive is part of the civil service and has the means to control CHCs through budgets and performance reviews and could impose its own objectives on CHCs. An alternative, advocated by ACHCEW, is the establishment of an independent national agency to take over the establishing role and with responsibility for training and development which is linked to standard setting and audit.

CHC staff, now RHA employees, will be employed in future by one health authority in a region. There are concerns that the CHC whose health authority holds the contracts for all CHCs in that region, might be vulnerable to particular pressure from that health authority.

Independence from local authorities as well as the NHS is now an issue for CHCs. CHCs are increasingly involved in community care and services managed by local authorities as well as the NHS. With half their membership directly appointed by local authorities, this may undermine the credibility of the CHC with the public and jeopardise its independence. There is also a potential conflict of interest for CHC members elected by the voluntary sector, from organisations who have contracts with health and local authorities.

User empowerment

CHCs have a duty to 'represent' local people's interests in health services. CHC members cannot themselves be representative of the community. CHCs are not composed of hypothetical 'typical' or 'representative' users. 'Typical' users do not join CHCs any more than they are elected to local councils or appointed to trust boards. However, CHC members and people from voluntary organisations are often accused of being unrepresentative by professionals and so their views are undermined.

Expecting a CHC to be representative in its membership is unrealistic and misunderstands the nature of the 'community'. The 'community' is made up of many different groups with different concerns and needs and priorities, that can often conflict. The issue is how people can be encouraged and enabled to participate and make their views heard in the health service and how CHCs can develop a mandate from the public and be accountable to them.

To do this they need to:

- ❖ Reflect local priorities and local concerns and the capacity to be flexible in choosing priorities and representing different communities.
- ❖ Cover a geographical area that people can relate to and understand.
- ❖ Assist local people to represent their own interests and make better use of the health service by providing information, advice, advocacy and help in making complaints.

CHC boundaries should reflect natural communities and, where possible, be coterminous with local authority areas since these are familiar to the public and follow the organisation of voluntary and local authority services. The development of locality purchasing also requires that localities are based on communities.

Rights and responsibilities

In order to participate, local people need to feel that it is worth their while and that their views will be both heard and respected. A public watchdog needs effective powers. Rights need to be based on a policy of openness and access to information. The logic of the market and competition between provider units is that information that may benefit a competitor needs to be withheld for commercial reasons. Increased openness is strongly supported in the Code of Practice published by the NHS Executive.²⁰ Secrecy excludes the public and can cover up incompetence and dishonesty.

Rights need to be enforceable and not open to interpretation. CHCs or members of the public would not necessarily exert these rights. However, rights ensure that there are increased opportunities for local involvement and legitimate public scrutiny.

Ways of strengthening public rights are outlined in Box 10.

Box 10 Developing the rights of CHCs and strengthening user involvement

Access to information

- ❖ Information about services requested by CHCs should be provided by trusts and health authorities.
- ❖ Agenda, reports and minutes of trust boards should routinely be available.
- ❖ Information about GP fund-holders' purchasing intentions, plans and contracts, practice budgets, practices' annual reports and accounts should be sent to CHCs.

Consultation

CHCs should be consulted on:

- ❖ Plans and changes proposed by health authorities and trusts.
- ❖ GP fund-holders' contracts with providers.

There should be a right to appeal in the last resort to the Secretary of State.

Meetings

CHCs should have the right to:

- ❖ Send an observer with the right to speak to health authority meetings.
- ❖ Send an observer with the right to speak to trust board meetings on request.
- ❖ Regular meetings with health authority members.
- ❖ Regular meetings with trust boards.

Visiting premises

CHCs should have the right to access to staff and premises where NHS or local authority care is provided, including GP practices. Guidance would be required to ensure that visits did not disrupt services or breach confidentiality.

Responsibilities for CHCs

CHCs, purchasers and providers should agree a code of conduct, outlining rights and responsibilities for both managers and CHCs and a procedure for dealing with disputes.

CHCs should be required to demonstrate how they are accessible to people in the community and how they will take account of views and report back to them.

Disputes about rights

There need to be arrangements for dealing with conflict and disputes that may arise between authorities, trusts and CHCs. There could be right of appeal to a panel, appointed by the NHS Executive with CHC and NHS representatives.

Accountability

The lack of formal accountability for CHCs is a major weakness. CHCs aim to represent local communities' views and it follows that members need to be drawn from those communities and have accountability to them. CHCs need to have close links and the means of getting feedback from different communities. Locality and voluntary organisation forums can provide a reference point for feedback and accountability for the CHC.

Members are the key link with local communities. CHC members need to have knowledge of different parts of the district or contact and understanding of specific community and client groups – as well as time and commitment. Members need to be appointed in a way that ensures these requirements are met.

Accountability also requires clarity about objectives and agreement on what services should be provided. For example, there should be a guaranteed minimum service around the core tasks provided to the public and to the NHS in **all** districts. CHCs have generally accepted the need for standards for their own services.²¹ However, *'outcomes' are not an appropriate measure for CHC performance*. CHCs' key role is in empowering users and so standards need to be set around how they undertake their duties: how they involve local people, how they consult them in reaching their decisions, and how open and supportive they are in helping local groups make their voice heard.

Resources

As the NHS locally and nationally is discovering, listening to local voices is neither cheap nor easy. It involves a long term investment of resources in the community to encourage and support local people and give them the confidence and information to participate in an informed way. Equally managers and staff need training and support to be able to listen and relate to patients and the public as equal partners in their own care. Considerable resources are being invested by all parts of the health service in developing patients' rights, information services and user empowerment. However, tangible results are often hard to discern.

CHCs have developed a role that was not envisaged in 1974, though for many CHCs the staff and budgets have not changed. Research indicates that relationships between CHCs and the health service are most difficult in areas with the fewest staff.²² Many CHCs are currently being run on a 'shoe-string'. Resources need to reflect what a public watchdog is expected to do.

12 Alternative models for community participation

What are the possible options for change? Some proposals are discussed below, including:

- ❖ Abolishing CHCs
- ❖ Giving CHCs more resources
- ❖ Introducing directly elected commissioning authorities
- ❖ Setting up community outcome councils
- ❖ Redefining CHCs as advisers to health commissions
- ❖ Re-establishing CHCs as community based agencies facilitating user involvement.

Abolition of CHCs

CHCs could be abolished and some of their functions could be taken over by health authorities. Non-executive members could be appointed for their local contacts and have the task of linking with local communities and providing feedback to the health authority.

Health authority decision-making may well benefit from non-executive directors having close local links, since empowering users and involving the community needs to be an integral part of their activities. However, members are appointed for their professional and management expertise. Where community activists are appointed as non-executive directors, there have been problems. If they do not fit in with the organisation's culture, they may not be reappointed.

Health authorities would also have to develop their own community networks, which might be more costly than existing CHCs. Because the health authority would not be seen as independent, management decisions might be based on poor quality information.

Abolishing CHCs without establishing an alternative independent agency would risk a return to the days of unchallenged professional vested interests. Openness to public scrutiny and accountability would be reduced.

Extra resources for CHCs

CHCs could continue as present with extra resources to carry out the work that they have taken on since 1990.

There are many advantages in investing some additional funds in strengthening CHCs. Extra resources for CHCs have generally been a good investment. In some regions there have been additional staff provided to deal with complaints or to carry out research projects. Where an additional member of staff has been appointed, this has made an enormous difference to the CHC and its ability to provide office cover and develop other areas of work.²³

As health authorities merge, several CHCs may relate to the same authority. There are now opportunities for specialisation with shared appointments of staff and joint member working groups for services, that cover more than one district. Specialist staff could be employed to deal with complaints from several CHCs that require representation skills, such as oral hearings of complaints against family practitioners or regional panels as proposed following the Wilson report.²⁴

Contracts from commissioners and providers could be given to CHCs to undertake specific work – such as needs assessment, working with local communities, monitoring contracts and providers. This could provide additional resources and avoid duplication with health authorities and providers. However, to safeguard the independence of CHCs, the general 'core' allocation must remain linked to the work programme of the CHC, as determined by the CHC itself.

Giving additional resources to CHCs does not, however, tackle the underlying problems CHCs face. More long term strategies are needed for CHCs to continue to be relevant, particularly as we move towards the primary care led NHS.

Directly elected commissioning authorities

Democratic accountability within the NHS currently comes only through the Secretary of State to Parliament. There is increasing interest in proposals for local authorities to become health commissioners across the whole range of health and social care.²⁵ Sometimes CHCs have got caught up in this debate. They are seen as a stop gap until there are elected health authorities or joint purchasing authorities covering health and local authorities.

Democracy and accountability in the NHS are major issues, but are not part of the debate about the future of CHCs. CHCs as independent, non-partisan community based agencies would have a role in helping individuals and groups to have their views heard, even if there were directly elected authorities.

Outcomes councils

The effectiveness of treatments from the patient's perspective is increasingly going to become the basis for purchasing decisions and have a vital part to play in debates on rationing and priority setting.

A proposal from John Spiers, Chair of the Patients Association and former trust chair, has suggested that CHCs might be reconstituted as community outcome councils, as part of a new framework for independent audit.²⁶ CHCs *'could be reshaped and properly funded, as a real test of how realistic consumer representation can be as a method of empowering patients'*.

Community outcomes councils would be independent of the health authority but have access to all the information held by the health authority. They would require purchasers to publish targets in every clinical discipline. They would have a role in educating and influencing public understanding of clinical uncertainty, effective and ineffective treatment and give informed patients a greater role in the management of their own care.

There are health outcomes councils in Australia.²⁷ However, health outcomes councils are made up mainly of health professionals with others including voluntary organisations. They are intended to be action-oriented and agents for change. Change comes through local people, mainly professionals, solving problems for themselves, not external inspectors or sanctions. Health outcome councils may be an effective way that health authorities may promote change, but it is difficult to see how they could become independent community based bodies.

It is therefore hard to see how CHCs could take on this role. How would members be appointed who had the skills and relevant experience? How would they be accountable for wielding these considerable powers? The proposal has attracted some interest but not so far gained wide support.

Advisers to health commissions

With the purchaser-provider split, CHCs and purchasers could develop a shared 'vision' of local health care. In order to avoid duplication and utilise their skills and experience, CHCs could become a **resource for health authorities** working on needs assessment, health promotion and contract setting and monitoring.

Though there are opportunities for joint working between CHCs and health authorities, there are also differences that will lead to conflict, in particular over priorities, where contracts are placed and where CHCs see health authorities as inefficient or lacking probity. In addition, if CHCs become too closely identified with purchasing decisions, they risk losing their credibility with the community.

Community development

Many of the weaknesses of CHCs come from their lack of focus and accountability. CHCs could be re-established with the role of **facilitating** and **enabling** groups and individuals to put forward their views and participate in decisions and planning.

Rather than directly 'representing' the public, CHCs could encourage and enable people from all groups in the community, in particular those who are generally at a disadvantage, to have their views heard. The CHC's role would be to help to give local people, as individuals and as groups, the confidence to speak for themselves.

CHC staff and members could act as links to health authorities and trusts and put them in touch with local communities and so help local people to put forward their views.

CHC members could be the key link to local people, responsible for liaison with different community groups and localities and providing feedback to managers. Where members and staff were involved in statutory committees, they would have arrangements for communicating with local people and providing feedback.

This role could involve:

- ❖ Holding conferences to bring together local users, carers and professionals to discuss particular health issues.

- ❖ Setting up forums in particular localities or for particular groups of users.
- ❖ Helping new community and self help groups to get started and to put forward their views, where there is no effective user voice.
- ❖ Acting as advocates and developing advocacy schemes.
- ❖ Providing information and advice, assisting complainants covering both health and social care.

The number of members on a CHC needs to reflect local circumstances. Members might be elected by voluntary and community organisations. There would need to be clear arrangements to ensure that different geographical areas, client groups and minority communities were included. Where a voluntary organisation also had a contract with the health or social services, this should be an interest that is directly declared with safeguards against conflicts of interest.

The CHC should be one among many community voices. It would be an informed voice and take an overall view balancing the interests of different groups. This may lead to conflict with some sections of the community.

This is the only model that meets all the criteria identified in section 11 (see Box 11). Many CHCs already work in this way and in the short term their terms of reference could be clarified and support, training and funding enhanced for their work in this way.

Box 11 Alternative models for community participation				
Would the agency be:	Independent of NHS?	Accountable to local people?	Empower users?	Have effective powers?
Abolition	No	No	No	No
Democratic representation	No	Yes	No	Yes
Outcomes councils	Yes	No	Yes	Yes
Partners with health commissions	No	No	Yes	No
Extra resources for CHCs, no other change	No	No	No	No
Community development	Yes	Yes	Yes	Yes

In the long term, structural changes would be required:

- ❖ To extend the remit of CHCs to community care.
- ❖ To change the way that members are appointed and clarify their accountability.
- ❖ To ensure protection from interference from the NHS Executive regional offices and appropriate training, research and monitoring of performance.
- ❖ To revise and extend rights especially in primary care.

13 Conclusions

The world has moved on since CHCs were set up. User empowerment and community involvement, novel concepts in 1974, are now important parts of the government's health strategy. Turning the national strategy into reality on the ground has been more of a problem.

The role of CHCs should be enhanced to enable them to empower users and local communities and to assist people, both as groups and individuals, participate in health and social care. This will require:

- ❖ An extension of the remit of CHCs into primary and community care.
- ❖ Clearly defined rights and responsibilities for CHCs, health authorities, local authorities, trusts and general practitioners.
- ❖ Standards for ensuring user participation and consultation, that are independently audited.
- ❖ Changes in the membership of CHCs and the ways in which they are appointed, and formal arrangements for reporting back to local people.
- ❖ Training and development for CHC staff and members and staff who work with them.

It is time to bring CHCs in from the margins of the health service and place them at the centre of user empowerment and community involvement. To ignore CHCs is to throw away twenty years of local experience and innovation. A national strategy that does not use enhanced CHCs to develop a local framework for empowerment and participation is likely to fail.

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