

CHC NEWS

A newsletter for community health council members and staff

Donna Covey sets out a programme for ACHCEW



ACHCEW director, Donna Covey

Having completed five months as ACHCEW director, Donna Covey has set things in motion at the Association. Her aim is to complement the work of CHCs by raising ACHCEW's media profile and developing channels through which CHCs can influence the national agenda. At the same time, ACHCEW will continue to offer services in support of CHCs. Last month Donna sent a newsletter to CHC offices outlining her plans. Here we summarise what she had to say.

Warning signs

There have been some warning signs from government, most obviously the budget freeze on CHCs. We should also take note of the lack of mention of CHCs in the recently published Health Bill.

PFI in ACHCEW

By the end of 1999, Donna wants to see PFI at ACHCEW – no, not a scam for bringing in extra money, but rather to be:

Proactive: not simply responding to the ideas of others, but having ideas of our own that they must respond to.

Focused: on the unique contribution CHCs can make, and co-ordinating those local activities, such as Casualty Watch, that can become national activities.

Influential: ensuring that journalists and government ministers at a national level understand they need to find out what CHCs think.

ACHCEW's Action Plan

We now have an Action Plan to raise our own profile and that of CHCs. The thinking behind this is

that CHCs should be seen as a vital part of building the new NHS – and become a harder target for attack by the government. Foremost among the planned activities are:

- The ACHCEW Commission on representing the public interest in the health service – see page 3 of this issue.
- The All Party Parliamentary Group on CHCs which was launched in February.

Over recent weeks, the main focus of our work has been lobbying on the Health Bill – see page 2.

We will continue to help CHCs deliver on their core priorities, and to provide information and advice, training and legal services, *Health Perspectives* and *CHC News*.

Finally, Donna gave a big thank you to the honorary officers and Standing Committee for their support and guidance since she arrived, to everyone in CHC Land for making her feel so welcome ... and especially to ACHCEW staff who actually do the work at the office.

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ISSUE 29, APRIL 1999

THE HEALTH BILL



CHCs promised consultation and inspection rights

The Health Bill has now completed its Committee Stage in the House of Lords. In such debates amendments are put forward, but after a response from a government minister – sometimes with an assurance that action will be taken – they are generally withdrawn.

ACHCEW has been busy drafting amendments and briefing Lords over the last few weeks, an effort which was reflected in the debate and which resulted in some welcome commitments from government ministers.

Consultation

Many proposed amendments concerned consultation. Ministers were reluctant to add details “on the face of the Bill”, but during the course of debate made commitments about how the government would respond through guidance and regulations.

Various amendments would have set out clear consultation requirements when a **Primary Care Trust** is created or dissolved. Responding for the government, Baroness Hayman said that:

- Consultation is mandatory for establishing PCTs.
- CHC Regulations will be amended to require consultation if a PCT proposes a substantial variation in services.
- There will be consultation over the dissolution of a PCT, but there may be exceptions: for example if a PCT needed to be dissolved urgently because patients were at risk.

Baroness Sharp moved an amendment which would require the Secretary of State to issue guidance on consultation concerning the **joint activities of local authorities and NHS bodies**. The guidance would specify who must be consulted (including CHCs). As before, the government was reluctant to include details “on the face of the bill”. However, speaking for the government, Lord Hunt commented “Of course we want CHCs to be consulted on proposals where appropriate ... And we want patients and carers to be consulted. But those groups will be properly involved in the development of the health improvement programme ... The powers to make regulations and issue guidance are the right way of ensuring that the appropriate people and organisations are consulted.”

Inspection rights

Baroness Hayman confirmed that PCTs will be placed in a similar position to health authorities and NHS trusts on a number of matters relating to CHCs. CHC Regulations will be amended to ensure that CHCs have inspection rights in relation to PCTs.

What next?

The Bill is expected to progress to the Commons around Easter. ACHCEW will continue to lobby for amendments. The newly formed All Party Parliamentary Group on CHCs should prove invaluable at this stage.

House of Lords Debates, Hansard, 25 February & 1 March

ACHCEW PUBLICATION

A Health Perspective on the Health Bill has been sent out for CHC members and staff.

FROM PARLIAMENTARY ANSWERS

CHC budgets

CHCs in England are currently struggling to see how they can curtail their expenses in the face of a budget freeze for the coming financial year. The situation in Wales, with a 2.4% increase, is slightly better, although the 1999/2000 budget is subject to confirmation by the Secretary of State. Allocations for CHCs by region for the year just ending and the forthcoming year are shown in the table.

*HL Hansard, 15 February, col WA 62;
18 February, col WA 92; 11 March, col WA 43*

Region	1998/99	1999/2000
North West	£2,997,000	£2,997,000
West Midlands	£2,294,000	£2,294,000
Trent	£1,783,000	£1,783,000
Northern & Yorkshire	£3,310,000	£3,310,000
South West	£2,009,000	£1,807,000
North Thames	£3,752,000	
South Thames	£3,938,000	
Anglia & Oxford	£2,004,000	
Eastern		£2,374,000
London		£4,192,000
South East		£3,597,000
Wales (*provisional)	£1,317,000	*£1,349,000

ACHCEW Commission

ACHCEW has launched its Commission on representing the public interest in the health service. The idea for the Commission stems from concerns about limited accountability in the NHS and the need for CHCs to "modernise". Despite major changes in the NHS in recent years, there has been little change in CHC Regulations, and in some cases little change in how CHCs work. Yet CHCs cannot afford to stand still if they are to have an effective role in the new NHS.

Membership

- The Commission will be chaired by the Editor-in-Chief of *The Observer*, Will Hutton.

Other members are:

- Professor Conor Gearty, Professor of Human Rights Law at King's College London and a practising barrister
- Susie Parsons, Chief Executive of the Commission for Racial Equality
- Professor Allyson Pollock, Head of the Health Services and Health Policy Research Unit at University College London and Director of R&D at the University College London Hospitals Trust
- Joyce Struthers, Chair of ACHCEW
- Stephen Thornton, Chief Executive of the NHS Confederation
- Stuart Weir, Senior Research Fellow in Democracy and Human Rights and Director of the Democratic Audit at the University of Essex.

Terms of reference and methods

Subject to adoption by the members of Commission, their terms of reference will be:

"To recognise that the ultimate purpose of the NHS is to serve the public interest and to identify the ways in which that public interest can be best served by the achievement of a full and effective system of public accountability."

The Commission will examine published work and take written evidence from organisations and individuals. It would welcome contributions from CHCs, regional CHC groupings and CHC staff.

The deadline for written evidence is the end of May 1999.

The Commission hopes to make an interim report on its findings at the ACHCEW Conference in July and a final report at a special conference in November.

Further details of the Commission and its membership have been sent to CHC offices.

Revalidation for doctors

In November last year, the General Medical Council (GMC) set up a steering group to explore the practicalities of implementing revalidation for specialists and GPs, i.e. a system requiring them to demonstrate on a regular basis that they are keeping up to date and remain fit to practise in their chosen field. In February Joyce Struthers, the chair of ACHCEW, was invited to attend a conference to discuss the steering group's report and at which the GMC would vote on the group's recommendations. At the conference, it was agreed that revalidation should be put in place for all registered doctors and that the steering group should develop further detailed proposals. This process will include consultation with user representatives, among others. The steering group is to report again to the GMC in May and November, and the GMC aims to have prepared and approved a fully worked up model within two years. The steering group's report is available at: www.gmc-uk.org/n_hance/good/reval.htm

CHC Performance Evaluation

In March Standing Committee agreed that the Performance Evaluation Framework for CHCs drafted jointly by HQS (a branch of the King's Fund) and an ACHCEW working party should be circulated for use in CHCs over the next 12 months. The Framework can be adapted by CHCs to meet their needs. To make this process easier, an electronic version of the Framework will be made available on request. It is proposed that a skills workshop should be organised at this year's AGM for those who will be using the Framework to monitor CHC performance.

ACHCEW Training

In addition to the training days we listed in *CHC News* last month, ACHCEW is offering an extra half-day seminar in London on 16 June:

- Data Protection and the Work of the CHC.

The Data Protection Registrar will consider offering these seminars locally if there is a demand – contact ACHCEW for information.

As for the other training sessions, the official deadline has passed and arrangements need to be finalised. But do apply (**quickly!**) if you are interested – there are still places on a few courses.

CHC involvement in PCGs

With 481 English primary care groups (PCGs) and 22 Welsh local health groups coming into being this month, control over a huge portion of the NHS budget will shift from secondary to primary care. CHCs around the country have been working hard to develop effective links with the new groups. Here are a few updates on activities.

New opportunities for Bristol's Local Voices

Bristol & District CHC's Local Voices Project Officer has been working with health authority colleagues on:

- Lay member recruitment – job descriptions/person specifications, preparatory workshops, member of shortlisting and interview panels for all 12 PCGs in Avon HA.
- Lay member support – designing and participating in induction/support meetings. One-to-one information/support on public involvement techniques.
- Public involvement initiatives in PCGs – an early priority is to identify one or two PCGs where it will be possible to work with lay members and others to develop public involvement.

Widespread involvement in London

The Greater London Association of CHCs has published a snapshot survey of the involvement of London CHCs in the configuration and development of PCGs. It shows that all 29 Greater London CHCs are pro-actively involved in the development of PCGs, although to a varying degree. The majority of health authorities see CHCs as having a vital role to play in developing links between local communities and PCGs. At the time of the survey (November 1998) 27 of the CHCs were negotiating both observer status and speaking rights on PCG boards.

Building on a partnership approach in West Sussex

West Sussex Health Authority and West Sussex CHCs have been invited by the Regional chairman to pilot working arrangements to improve public accountability and involvement in the local NHS. The CHCs believe that collaborative working arrangements should be the cornerstone of their relationship with PCGs and they have published a paper setting out proposals for achieving this aim. *Building a Partnership* looks at potential difficulties for PCGs and CHCs, mutual gains from collaboration and proposals for effective joint working. Among the recommendations are that a CHC member should have observer status with speaking rights on each PCG board and that a CHC member should assist the PCG lay member in liaising with (or developing) Patient Participation Groups. Other recommendations concern quality monitoring and input into the Health Improvement Programme.

ACHCEW PUBLICATION

Primary Care Groups – the early guidance

This Health News Briefing has been sent to CHC offices.

Ethnic minority involvement in PCGs

by Georgina English, Commission for Racial Equality

As PCGs become established, there is growing concern that, once again, the need for mechanisms to involve black and minority ethnic groups in a dialogue which properly represents their views is being overlooked. Direct representation by ethnic minority shadow board members as professionals or lay members is limited. The very tight timetable for setting up PCGs, including the appointment of lay representatives, resulted in a process which excluded many small and hard-pressed organisations working with ethnic minority communities. Even more worryingly, Racial Equality Councils across the country are reporting that well established forums which could have been expected to form a basis for accountability between the PCGs and black and ethnic minority communities are being marginalised.

ACHCEW and the Commission for Racial Equality (CRE) would like to hear from any CHCs which are working with black and ethnic minority organisations, networks or focus groups to secure a mechanism through which the views and concerns of ethnic minority communities will be regularly fed into primary care planning and commissioning. The pattern that is established now will have a major impact on whether the NHS can reduce health inequalities for ethnic minorities.

Donna Covey, the director of ACHCEW, has recently signed up to the CRE's Leadership Challenge – a commitment by leading figures to promoting measurable racial equality objectives in the organisation through practical action. ACHCEW joins many key national health sector organisations including the NHS Confederation and the General Medical Council. The CRE and ACHCEW have a common interest in improving opportunities for ethnic minority user participation in the NHS. It is crucial at this stage that we are informed by local experience of both good and inadequate practice so that effective strategies can be developed. We would value your help.

Please write to Georgina English, CRE, Elliot House 10/12 Allington St, London SW1E SHE, Phone 0171 932 5340, Fax 0171 932 5406 or Gary Fereday at ACHCEW

First off the starting block:

Lessons from GP commissioning pilots for Primary Care Groups

Emma Regen, Judith Smith & Jonathan Shapiro
Health Services Management Centre, University of Birmingham, £15, Phone Maureen Alcock, HMSC, on 0121 414 7050

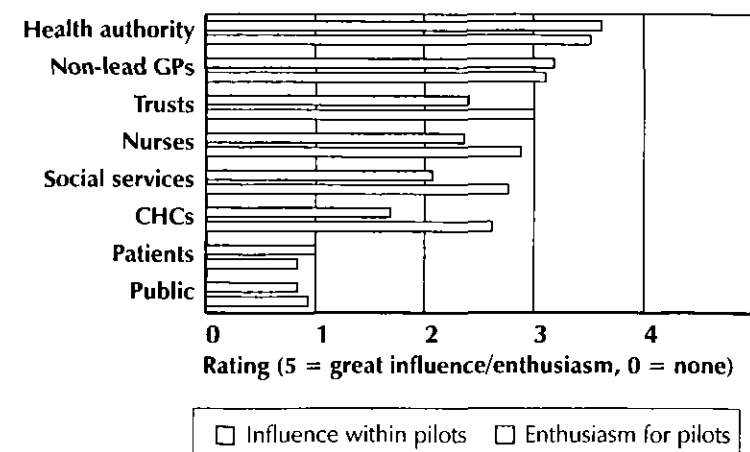
The 40 GP commissioning pilots which started up in April 1998 throw an interesting light on what may be expected as PCGs develop. This substantial study gives details of the pilots during the first 5–6 months of operation.

One section looks at the involvement of various stakeholders, including CHCs, patients and the public (see graph). The research found very little evidence of direct patient or public involvement, although some exceptions could serve as a model for others. There was more involvement of CHCs, although they found it difficult to participate in sub-groups below board level because of a shortage of people who could take on the work. An interesting finding, which has also begun to emerge in what ACHCEW hears from CHCs, is that most CHC representatives saw a major part of their role as advising groups on how to engage members of the public and patients more directly. In other words they should not be regarded as "proxy" users, but rather as "a route into the community".

Although there were several examples of good practice, some groups had failed to engage CHCs, let alone the public. While most of these acknowledged the need to involve patients and the public, it appears that they were willing to put the issue on the back burner. If the same pattern emerges as PCGs develop, the relevant CHCs will have their work cut out to see that public involvement becomes an early reality.

Influence and enthusiasm of stakeholders as rated by the lead GPs of commissioning pilots

Source: First off the starting block



Arrangements for PCTs

The Department of Health has sent a paper to PCGs and others on Primary Care Trusts (PCTs), including proposed arrangements for their governance.

There will be two types of PCT:

- "Level" 3 PCTs will commission most hospital and community health services.
- "Level 4" PCTs will commission these services and can provide community health services.

One aim of the paper seems to be to reassure primary care professionals that they will be "in the driving seat", while providing for public accountability and involvement and probity. To this end, PCTs will have a lay majority board, and a professional majority executive.

Trust executive

Role: The "engine room". It will initiate and do the detailed work of the PCT and "lead" the board through detailed thinking on priorities, service policies and investment.

Make up: Chief executive, finance director and social services officer nominated by the local authority and professional members as follows:

- Level 3 PCTs: up to 7 GPs, 2 nurses and a professional with public health/health promotion expertise.
- Level 4 PCTs: 10 clinicians are envisaged, with significant representation from general practice balanced with nurses and other community and public health professionals. Some will be appointed to carry out specific functions.

Trust board

Role: Accountable to the health authority. Will hold the executive to account and, in the last resort, have the final say. It will need to approve all executive appointments and reserve some other decisions to itself, such as payment of executive members and entering into contracts under the Primary Care Act.

Make up: Chair and 5 lay members (open to local authority elected members) – all 6 appointed by the Secretary of State, the chief executive, the finance director and 3 professional members drawn from the executive. The professionals on the board must include the director of clinical governance, at least one GP and one nurse.

COMBATING AGEISM IN THE NHS

Age Concern calls for an audit

Despite official policies against age discrimination, in practice there is a great deal of ageism in the NHS. So MPs were told by Dr Vince Cable, a Lib-Dem MP, when he sought leave to introduce a Private Member's Bill, *Age Limits on Health Care*. The Bill would prohibit the refusal or delay of treatment on the basis of age and establish an inquiry into the prevalence of age discrimination in the NHS (*Hansard*, 16 February).

ACHCEW is having discussions with Age Concern about the extent of ageist decision-making in the NHS and what can be done about it. In particular we are concerned about "backdoor euthanasia". Allegations have been made that 40 deaths at a Derby hospital resulted from a policy of starvation and dehydration of elderly patients with dementia. The police are investigating these and other suspicious deaths of elderly NHS patients. In January 1997, ACHCEW highlighted allegations of similar practices in its Health News Briefing, *Hungry in Hospital*.

Other ageist practices in some parts of the NHS include:

- refusal of elective surgery
- "do not resuscitate" policies
- management of GP waiting lists to reduce the number of "expensive" elderly patients
- telling elderly people to put up with a condition for which younger people would be treated.

What is more, NHS resources are allocated in a way that limits the availability of treatments for and research into medical conditions which primarily affect older people.

In a recent Health News Briefing, ACHCEW's legal officer described how some practices could be in breach of Articles 2 and 14 of the European Convention on Human Rights. This is to be incorporated into UK law in the Human Rights Act that will come into force in January 2000.

ACHCEW officers have met with an Age Concern legal officer to discuss how we can work together to identify and challenge ageism in the NHS. Age Concern has called on the government to initiate an audit of age discrimination in the NHS. If you are aware of any ageist policies or practices, they would like to hear from you. Age Concern can be contacted on 0181 765 7511.

Alliance Against Ageism

Determined to translate widespread concern about ageism into local action, Liverpool Central & Southern CHC has set up an inter-agency group, *Alliance Against Ageism*. The group has produced a Statement of Rights for Older People in Hospital on the basis of which they have established discussions with the Director of Nursing at the local NHS Trust. She has undertaken to take the Statement to the trust board, for promulgation to all staff. Meanwhile the Alliance is to launch the Statement publicly and invite new members to join at a major event in May. As mentioned in last month's *CHC News*, CHCs have recently been sent material from the Dignity on the Ward campaign by Help the Aged. Liverpool Central & Southern CHC is keen to take up the campaign's call for input from local organisations.

CASUALTY WATCH: A THANK YOU TO ALL WHO TOOK PART

Donna Covey has received this letter on Casualty Watch from Malcolm Alexander, who asked her to pass on his comments to all CHC News readers.

I'm writing to thank you and your colleagues for the brilliant work that was achieved in January during National Casualty Watch. The process of planning the event, collecting and analysing the data and producing the excellent report, was carried out with great skill and expertise. The results are a great testimony to the effectiveness of the team at ACHCEW.

I was also very impressed at the quality, volume and effectiveness of the press coverage and felt that it displayed the value of CHCs, and demonstrated their potential for influence at a local and national level. We can achieve so much if we co-ordinate our work and utilise our enormous knowledge and skills.

I also want to thank all the members and staff across the country who gave their time and commitment to Casualty Watch, and made possible this landmark in collaboration for health. I think we have created much more than a list of casualty waits – we have created a community of Health Councils able to operate in a highly organised and sophisticated way to improve the health of the nation. We have much to be proud of.

Malcolm Alexander
Chief Officer, Southwark CHC

SPREADING THE WORD ABOUT CHCs

Taking the CHC message to Europe

by Barrie Taylor & Chris Dabbs

CHCs are "the jewels in the crown of the NHS". This was a description given by Mikko Vienonen, of the World Health Organisation (WHO) Regional Office for Europe at last year's ACHCEW Conference. He was attending at the invitation of Citizens Health Information Network & Alliance (CHINA) – a multi-agency project involving WHO, ACHCEW, the NHSE, the Kings Fund, the Centre for Health Services Studies at the University of Kent and, latterly, UNISON.

Since then, CHINA has kept in touch with the people it placed in CHCs across England & Wales last summer and has received information and invitations to contribute to the development of citizen involvement in health care in Europe. In February Barrie Taylor, the CHINA project leader / South West Herts CHC chief officer and Chris Dabbs, Salford CHC chief officer, were invited by the German government to attend a conference, *Citizen Participation – A challenge to different health care systems*. Although there was a distinct German flavour to proceedings, contributors came from across Europe and the USA.

Presentations and discussions ranged from fundamental issues of philosophy and accountability to the involvement of individual patients in care decisions. The conference demonstrated that most countries are still struggling to find effective ways to involve lay people. The tensions between professional, management and lay interests seem prominent everywhere. However, some of the basic principles are now becoming well established, as perhaps best outlined in the *Ljubljana Charter on Reforming Health Care in Europe* (1996).

Patients' rights and citizens' participation have gradually found their way onto most health care agendas across Europe and the USA. However, comprehensive public policy has been developed in only a few countries, including the Netherlands, Scandinavia and the UK. In the Netherlands, the government gives considerable financial support to an independent *Federation of Patients and Consumer Organisations* and its members. Health is largely the responsibility of municipal authorities in Scandinavia, with a direct link to citizens. There are also many good examples of patient/citizen representative bodies in other European countries. It is noticeable that the countries where such developments have made most progress are those with systems of socialised medicine. Lessons from these advances are now being put to use in many European states with insurance-based systems – the challenges appear to be the greatest in the eastern European countries with a

legacy of centralised political control. Many countries are now showing particular interest in the UK model of citizen involvement – as was demonstrated in Bonn when over three boxloads of literature on CHCs disappeared within as many minutes.

There is of course, no model of citizen or patient participation that can simply be replicated between countries – what is acceptable in the UK may not easily fit into the Ukraine. However, there is much to learn from one another. The momentum for change is building up and lay participation in health decision making across Europe seems inevitable. This will be boosted by the forthcoming Council of Europe publication on citizen and patient participation in decisions affecting health care. CHCs are poised to influence a wider agenda than their own in the UK, if they are willing to develop their international contacts. At the same time, they will benefit greatly from the support and the lessons that colleagues in Europe can and will offer.

For further information on the CHINA project or the Bonn Conference please contact Barrie Taylor on china.chcda@btinternet.com or Chris Dabbs on ChrisDabbs1@compuserve.com.

A CHC voice on the Epilepsy Task Force

Winchester and Central Hampshire CHC has a special interest in epilepsy, so a few years ago ACHCEW invited Christine Allen, the CHC chief officer, to represent CHCs on the Epilepsy Task Force. Christine has found the Task Force a forward thinking organisation which demonstrates the benefits of clinicians, service users and user representatives working together to reach a consensus.

A recent meeting looked at a draft of the Epilepsy Services Development Kit, which sets service standards, documents provision and suggests practical actions. The meeting also aimed to commit participants to certain actions, particularly in providing a wider range of services to local people with epilepsy and in providing more evidence of integrated good practice between primary and secondary care.

The most controversial part of the Kit is a 4-grade ranking of epilepsy services. Although there may be disagreements over the accuracy of the rankings, the information should provide a useful tool for CHCs to use when questioning local trusts and health authorities. At the meeting Christine suggested that individual CHCs should be circulated with information and that Regional Associations of CHCs should be asked to put the Kit on the agenda at a regional level.

Birmingham CHC gives evidence to the Commons Health Committee

Birmingham CHC has recently given written evidence to the House of Commons Health Committee's inquiry into Future NHS Staffing Requirements. The context for the submission was that Birmingham Health Authority is proposing a radical plan to restructure the hospital sector so that £50m can be invested in primary care. While the CHC welcomes the aim of developing primary and community services, it is seriously concerned at the impact the plan would have on the secondary sector. In its evidence the CHC argues that the HA has failed to analyse current or future needs for in-patient care or the implications of the plan for the caseload and staffing of hospital trusts. Furthermore, the proposed models of care have not been tried out or costed on an adequate scale, so it is not possible accurately to predict what saving will be achievable by implementing them. In short, the CHC predicted a crisis if the plan is put into effect.

Barnet CHC wins rights on PFI scheme

Barnet CHC is delighted that it has reached an agreement with Wellhouse Trust and the consortium, Metier Healthcare, to grant the CHC visiting rights at a new PFI extension to the existing Barnet General Hospital. The CHC has been attending regular meetings on PFI for the last four years while the contract has been under negotiation and it is enthusiastic about the scheme, which is to include IT and communications systems as a major component. The final contract between the trust and the consortium states that the CHC has the right to attend their joint steering committee meetings and to be consulted on any changes during the 34 year life of the contract.

Health Service Journal, 25 February

CHC MEMBERS' LIABILITY

CHC members' personal liability has long been a matter of concern. CHCs are unincorporated organisations, and so have no separate legal identity of their own. CHC members are therefore directly responsible for liabilities which the CHC cannot meet from its funds. What is more, CHC members are held "jointly and severally" liable for CHC debts. This means that if one or more members does not meet a portion of a debt, the remaining members remain liable to pay that portion. An individual member is also liable in the case of a civil claim being made against him/her.

Some time ago, as a result of ACHCEW representations, CHC members were offered some indemnity:

"An individual CHC member who has acted honestly, reasonably, in good faith and without negligence will not have to meet out of his or own personal resources any personal civil liability which is incurred in execution or purported execution of his or her CHC functions."

This indemnity left CHC members with no cover either if they were found by the courts to have acted negligently or if the NHS Executive decided that they had not acted reasonably.

ACHCEW continued to make representations to the NHS Executive and a new form of indemnity has now been produced. It reads:

"An individual CHC member who has acted honestly and in good faith will not have to meet out of his or own personal resources any personal civil liability which is incurred in execution or purported execution of his or her CHC functions save where that person has acted recklessly."

This wording is an improvement, although the requirement not to have acted recklessly is not one that applies to NHS trust and health authority board members.

It appears that, as previously, this form of indemnity will **not cover legal costs incurred by CHCs taking legal action.**

No details have been provided about how a member can seek to activate the indemnity or to appeal against any refusal by the Secretary of the State to apply the indemnity in an individual case. However, in the first instance any claim should be directed to the appropriate Regional Office of the NHS Executive or the Welsh Office.

Note: Items in CHC News present the views of contributors and do not necessarily reflect the views of ACHCEW.