CHC NEWS

A newsletter for community health council members and staff

Setting priorities for ACHCEW

Donna Covey took up her post as ACHCEW director on 12 October. Here she introduces herself to readers of *CHC News* and sets out her priorities for action.

I am delighted to have this opportunity to use *CHC News* to introduce myself to CHC members and staff across the country.

Since taking up my post in October, I have become aware both of the tremendous challenges we face, and of the depth of talent and commitment in the CHC movement.

This is a defining moment for CHCs. The various government White and Green Papers on health since the election have said little about CHCs. In some ways this is disappointing, but in others it offers great opportunities. The opportunity for CHCs, and particularly ACHCEW, is to develop our own model of patient and community participation in health care, with CHCs at its heart. If we can do this, we will go into the new millennium stronger and with a renewed sense of purpose.

I have set myself a number of tasks for my first few months in office.

My first is to meet as many people as possible. I already have a programme of visits agreed covering every Regional Association and the Welsh Association. Strong grassroots input is key to our survival, especially with the challenges of devolved government in Wales and the English regions.

I recently attended the Society of CHC Staff conference, which provided a welcome opportunity to meet a wide range of CHC staff.

My second priority is to build our profile amongst opinion formers.

Work is under way in setting up an all-party parliamentary group on CHCs. This will raise our profile in Parliament, and also give us a team of MPs and peers of all parties looking out for our interests. I hope that all CHCs are encouraging their MPs to get involved.

The launch of the group is set for January 1999.

We also need to raise our media profile. I was a panellist on Radio 4's *Any Questions* during my first week in post, and am now working with the ACHCEW's information team to put in place a media strategy for the future.

The Queen's Speech is expected to include reference to health legislation in the forthcoming parliamentary term. This a wonderful opportunity for CHCs, through ACHCEW, to engage in the debate around the shape of public accountability in the new NHS.

The government does not have a blueprint for the future for community accountability in the health service at local level. We have a real opportunity to develop a model, and fill the gap. We either change, or have change imposed upon us.

I am confident that the ideas, the good will and the enthusiasm are all out there. My job, above all, is to harness these, and develop a coherent direction for the future.

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In this issue:

ASSOCIATION OF COMMUNITY HEALTH COUNCILS FOR ENGLAND & WALES
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Representing CHCs at Parliament

On 10 November ACHCEW's chair, Joyce Struthers, and research and information officer, Gary Fereday, gave evidence about the workings of the NHS complaints procedure to the House of Commons Select Committee for Public Administration.

ACHCEW has been lobbying the Committee (chaired by Rhodri Morgan MP) for some months following the publication of the Health Service Ombudsman's Annual Report. This year's report omits useful statistical information that previous reports have included. The report even failed to name the trusts investigated.

Prior to the session, we provided the Committee with a memorandum outlining our key concerns about the complaints procedure and the Ombudsman's report. In reply, the Ombudsman's memorandum states that the next annual report will contain the names of trusts investigated and that consideration will be given to the other issues raised. We have welcomed this as a positive development and hope to maintain this constructive dialogue with the Ombudsman's office.

Our evidence to the Committee outlined concerns raised by CHCs, including monitoring local resolution, the role of convenors and the time some Independent Review Panels are taking to start up. The Committee explored a number of issues including no fault compensation schemes, whether staffing shortages in the NHS were creating problems and the wider role of CHCs.

ACHCEW's parliamentary activity will be increased further when the proposed all-party parliamentary group for CHCs is formed early next year.

National patient and user survey

The national survey of patient and user experience, promised by the government in its NHS White Papers, was launched in October.

- Each year there will be a core survey, mainly about primary care services. A questionnaire was sent in October to 50,000 people.
- There will also be a rolling programme to look in depth at selected areas. The topics for this round are coronary heart disease and cancer services. Subject to approval from Research Ethics Committees, these surveys will be distributed in January, to 50,000 people in each case.

The work is being overseen by a reference group on which ACHCEW is represented by the ACHCEW chair, Joyce Struthers, and information officer, Angeline Burke. ACHCEW was not invited to the first meeting of the reference group, and so had minimal input before the core questionnaire was finalised. In addition, there is very little patient/user representation on the group: just ACHCEW, the College of Health and the National Consumer Council. While all three organisations welcome the idea of an annual patient/user survey, they all have reservations about the details of the project. These include concerns about aspects of confidentiality, fully informed consent from respondents and a lack of questions seeking qualitative data.

ACHCEW will have greater opportunities to have an input into next year's core survey and this year's surveys on coronary heart disease and cancer services.

Staff involvement in the NHS

Earlier this year an NHS Taskforce was set up to explore approaches to staff involvement, and to recommend how frontline NHS staff can work with local managers and clinicians to improve services. In November, Frances Presley, ACHCEW's enquiries officer, attended a seminar which aimed to share interim findings and recommendations and to get feedback. This was the first time that CHCs had been included in the process, either as NHS staff or as patient representatives – and no other user representatives were present. Frances raised this issue, stressing the importance of patient representation in planning and delivering services. This will also have beneficial results for staff participation.

Participants were asked how they could support staff involvement and ensure that it happens. The example ACHCEW gave was of CHCs forming closer links with staff groups to pursue issues of common interest.

The Taskforce aims to present ministers with:

- a compendium of best practice
- a performance management framework
- recommendations on targeted support and advice to NHS trusts and health authorities.

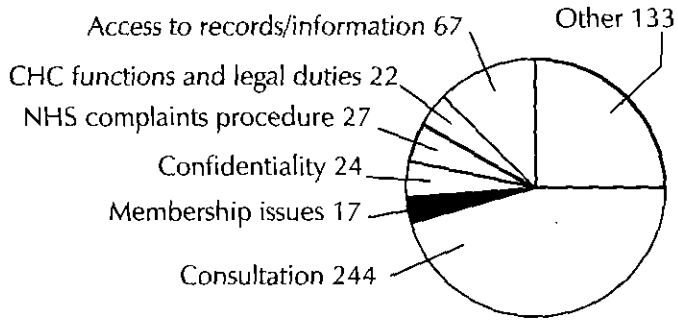
The emphasis throughout is on "employee partnership", in which managers and staff work together to tackle problems. Although this positive attitude to staff involvement is to be welcomed, there will be occasions when staff and patient interests will require independent representation and safeguards.

Enquiries about consultation still top the list

Figures on enquiries to ACHCEW's legal service show that consultation rights and responsibilities remain the main topic on which CHCs want advice (see graph). CHCs are also seeking advice on an increasingly diverse range of legal issues. It is encouraging that, despite the volume and complexity of work the service handles, a recent survey of CHCs showed a very high level of satisfaction with the speed and quality of response.

Subject of enquiries received from CHCs

1 April to 30 September 1998



MAILINGS

ACHCEW has sent these documents to CHC offices:

➤ **The Bristol inquiry: survey of CHC views**

At this year's ACHCEW conference, delegates passed a resolution calling on ACHCEW to survey member CHCs to obtain their views on openness and accountability in relation to clinical performance. The aim would be to present the findings at the inquiry into the deaths of children following surgery at Bristol Royal Infirmary. ACHCEW has written to CHCs asking for their views and any evidence on the issue. We have also asked for views on a discussion paper from the Trent Regional Association of CHCs about information which should be available to patients for choosing a consultant and hospital.

➤ **A *Health Perspective* on Casualty Watch**

➤ **Reports of this year's AGM group sessions**

➤ **Legal briefings on:**

- The effect of restrictive covenants on hospital land
- Powers of attorney

➤ **Training bulletin**

Issue 2 of the bulletin has now been distributed. There is a copy for each CHC member.

DoH intervenes on GMC guidance

The General Medical Council (GMC) is responsible for setting standards and advising doctors. Current GMC advice on the duty of doctors to maintain patient confidentiality is to be found in its booklet, *Good Medical Practice*. In response to changing practices in the NHS (such as increasing electronic storage and transmission of patient information and new financial audit procedures) the GMC has drafted new guidance. ACHCEW was consulted and made strong representations about the need to limit disclosure to those providing care unless the patient explicitly consents to wider disclosure, e.g. for research and audit. The GMC obtained legal advice which, while not going as far as we would like, does confirm that patient consent is needed for wider disclosure.

The Department of Health appears to be concerned that the GMC's advice amounts to a challenge to the current approach to confidentiality within the NHS (that information can be widely shared within the NHS without patient knowledge or explicit consent). The Department has asked the GMC to delay issuing its guidance and to make changes. CHCs should be concerned about this attempt to put pressure on the GMC, particularly as the courts have traditionally followed GMC guidance in deciding whether there has been a breach of patients' rights to have their personal medical information kept in confidence. CHCs may wish to take this matter up by contacting their MPs and ACHCEW.

Charges for NHS services

All NHS services must be provided free of charge unless charging is expressly allowed by law. Various pieces of legislation allow charges may be levied on:

- NHS prescriptions
- NHS dental treatment
- Sight tests
- Glasses and contact lenses
- Travel to and from hospital for NHS treatment
- Wigs and fabric supports (including elastic hosiery, surgical bras and spinal supports)
- Emergency treatment after injury in a road traffic accident.

No charges can be levied for any other NHS service, although users may be asked for a deposit on loaned equipment. This means that wheelchairs, walking aids and artificial limbs must be provided, maintained and repaired for free.

ACHCEW will be producing a detailed briefing to clarify and explain NHS charges and circumstances in which assistance with the costs might be available.

Health needs of minority ethnic community women
Darlington & Teesdale CHC

Black and ethnic minority communities: perceptions of local diabetic services
Preston CHC

The overwhelming message from these two reports is that much more action is needed to overcome language and communication barriers which face members of ethnic minority communities. The message is particularly clear in the Darlington & Teesdale CHC report, which draws on interviews with local women and health staff and a conference organised by the CHC and the local Health Promotion Service. Many of the women who contributed have little contact with the NHS: a lack of accessible information in their own languages leads to a low awareness both of health problems (e.g. cancer and depression) and of services available. This is compounded by a perception that visits to a GP may not be helpful because of language barriers and a need to use interpreters – often members of the family who inhibit frank discussion. In turn, this means that the women do not gain the knowledge about their health condition.

Interpreting services are available (although not all health care providers were aware of them), but without breaking through the first barriers – awareness of health problems and of services – ethnic minority women will continue to be under-served. The CHC urges all health service providers to display and distribute more multilingual information. Translated information could be made more accessible through a community centre for ethnic minority people and possibly through a "lending library" system. There is also a need for a female bilingual worker to provide health advice.

In the Preston CHC report, language barriers are slightly less prominent because all the people interviewed are already users of the local diabetic service – more general problems such as waiting times start to figure in their experiences. It is likely, however, that many have slipped through the net because of lack of general awareness: diabetes is about five times more common among Asians than non-Asians and often goes undiagnosed. What is more, awareness-raising literature in languages other than English might well prevent some people from developing diabetes in the first place. But even among existing diabetic service users, there were numerous examples of failure to overcome language barriers. For example, some find testing kits difficult to use because the instructions are in English. Many of the recommendations overlap with those of the Darlington & Teesdale report – indeed, others have been making similar calls over recent years. What is needed is for the NHS to act on their advice.

Funding to meet language needs

The Department of Health has announced a 3-year freeze on the formula used to allocate funding within of the NHS. During this time, the formula will be a reviewed to ensure that allocations match need.

In the meantime, three final changes to the existing formula have been made, including the following: "a monetary adjustment to supplement the formula for the extra costs of interpretation, advocacy and translation services, so Health Authorities with large ethnic minority populations who experience difficulties with the English language are fairly treated."

DoH Press Release, 10 November

READER'S LETTER

NHS Board Meetings

As a recently appointed member of the CHC, but a long-time regular attender at CHC and trust board meetings as a member of the public, I offer my comments on trust board meetings and the involvement of the public at them (*CHC News*, Issue 24, page 7).

Our local NHS trust allows public questions at the very end of proceedings. I much prefer the CHC's style of public participation whereby questions are invited at each stage of the agenda. Though not strictly a public meeting, all public "observers" are made to feel welcome – not simply "tolerated".

I have to say that few people take advantage of the facility to attend, and the local trust chairman has invited me to submit ideas which might increase interest without interfering with the business in hand. Announcements in the local press could be more prominent and invitations to attend and submit written or oral questions should be included. The agenda items chosen should encourage this.

Our local trust had some problems in 1993/94 including allegations which arose because of a lack of complete transparency. The present board, which includes only about 25% of the 1993/94 membership, has genuinely attempted to allay the public's fears of a secretive culture continuing. The encouragement of more public involvement can only reinforce this.

Harry Horne
Member of Burnley, Pendle & Rossendale CHC

Thanks to Harry Horne for his letter, and we hope that he may have set the ball rolling ... we are keen to publish letters, so please write in with your views on items in CHC News or about your CHC activities.

CHCs working for public involvement in PCGs

CHCs throughout the country are seeking ways of ensuring public involvement in primary care groups (PCGs). In Trent Region CHCs are using a range of approaches to fostering the participation of patients and the wider public in local health services:

- **Rotherham CHC**'s locality commissioning officer has been seconded to the local health authority to work on a Public Involvement Strategy.
- **Leicestershire CHC** is working with its local health authority and chairing the Public Involvement Sub-Group (which involves lay representatives) to inform PCG strategy.
- **Central Nottinghamshire, Bassetlaw, Barnsley** and **Southern Derbyshire CHCs** are all working with local health agencies to form a steering group to develop a framework for public involvement.
- **North Derbyshire CHC** is playing a key role and using its experience of primary care projects to inform a Public Involvement Strategy.

In North Thames Region **West Essex CHC** has drawn up a short document outlining the CHC's view of the role it can play in relation to PCGs and the contributions it can make to their work. These contributions include offering workshops to PCG boards to help them devise a public involvement strategy, monitoring local services, sharing information on trends in complaints and feeding information into the development of the local Health Improvement Programme. The CHC anticipates that a CHC member and officer will have speaking rights at board meetings, but that they will not have voting rights.

We would welcome examples of what other CHCs are doing in this field, and particularly any articles describing CHCs' experiences with the early development of PCGs.

A potential conflict of interest

During the consultation on PCGs ACHCEW did not call for CHCs or individual CHC members to be full members of PCG boards. Such membership could lead to a perceived conflict of interest, thereby damaging public confidence in a CHC's independence. At its September meeting ACHCEW's Standing Committee confirmed that it would be more appropriate for CHCs to seek observer status with speaking rights and to support lay members on PCG boards. A way of achieving this would be to seek Associate Membership which, as outlined in official guidance, appears to offer speaking observer status.

A letter on this issue and on some contributions which CHCs can make to public involvement in PCGs has been sent to CHC offices.

NHS Complaints
Are we listening, acting and improving?

Ros Levenson & Nikki Joule
for Croydon HA and Croydon CHC

This is a substantial piece of work involving questionnaires to NHS trusts, staff who had been complained against, GPs and complainants. There were also interviews with a wide range of those involved in complaints. The wide-ranging findings make interesting reading.

The working of the system seemed to be greatly influenced by the calibre of complaints managers and convenors. In general practice the results were particularly varied, with many practices recording no complaints over a year, while one recorded as many as 27. Interestingly, the practices with most complaints seemed to make the most positive comments about the system. A rare criticism of the CHC – "Croydon CHC should be more impartial rather than encouraging patients to complain regarding trivialities" – came from a practice which said it had received no complaints in the relevant year.

POPAN

POPAN – Prevention Of Professional Abuse Network – is a charity which aims to:

- help people abused by health or social care professionals
- prevent future occurence of such abuse

Last year POPAN dealt with cases of physical, sexual and emotional abuse; alleged abusers have included doctors, psychotherapists and nurses. The results for some of the targets of abuse have been devastating.

Among other activities, the charity offers support to those who have been abused and provides information and advocacy to those wanting to make a formal complaint.

For more information, contact: POPAN, 1 Wyvil Court, Wyvil Rd, London SW8 2TG; phone: 0171 622 6334.

New health minister

In the mini-reshuffle following Ron Davies's resignation as Secretary of State for Wales, Paul Boateng left the Department of Health. His replacement as Parliamentary Under-Secretary of State for Health is John Hutton, MP for Barrow & Furness. Mr Hutton will have responsibility for social care and mental health issues.

Relieving the winter pressures

The government has announced a one-off cash injection of £250 m for the NHS to deal with winter pressures on the service. The money is intended to tide over the NHS until the extra funding announced in the Comprehensive Spending Review starts to become available next April. It is to be allocated to develop new ways of working between health and social services.

Times/Independent 4 November

CHCs will have a chance to assess how well hospital A&E departments are coping with winter pressures when a nationwide Casualty Watch is repeated in January. ACHCEW hopes that all CHCs will agree to take part. Details in November's Health Perspective.

Huge variations in NHS costs

The cost of a cataract removal with a lens implant can range from £337 to £1659 in NHS hospitals. This is the most striking of the variations in a new set of figures published by the Department of Health, but other procedures also show striking variations. Some 90% of trusts perform operations at a cost within 20% of the average, but a few are way outside this range. The health minister, Alan Milburn has described the discrepancies as "unexplained" and "unacceptable". High cost hospitals are to face touch efficiency targets.

Individual hospitals and hospital managers have called for caution in interpreting the figures. Four of the five hospitals listed as most expensive are teaching hospitals: these are likely to treat patients with particularly complex needs. Another major cause of bias is that hospitals use different systems for allocating overheads – some of the discrepancies may reflect no more than differences in accounting systems. Some of the variations however reflect genuine differences in efficiency. Moorfields Eye Hospital, for example, is a teaching hospital, but is in the list of low-cost trusts because it performs an unusually high proportion of cataract operations on a day-case basis.

Guardian, Times 3 November

Wasteful prescribing

GPs are responsible for the widespread use of medicines which are "less suitable for prescribing" and therefore potentially a waste of resources, according to the campaigning group, Social Audit. The latest edition of the British National Formulary, used as a reference by prescribers, uses symbols to flag up about 100 drugs which are "less suitable" because of low effectiveness or dangerous side-effects. Social Audit has analysed official prescribing figures and concludes that £109 m was spent in England on these drugs in 1997.

Reactions

- Charles Medawar, who runs Social Audit, comments that a given drug might be right for a given patient, but doctors should be especially ready to justify the prescription where the drug is judged "less suitable". He recommends that each GP should be told how many prescriptions s/he is writing for these drugs and how much they cost.
- Joe Collier, the editor of the *Drug and Therapeutic Bulletin*, argues that the burden should be on government ministers rather than GPs. The licensing system should be used more effectively, and ministers should seriously consider not re-licensing a drug "if there is any hint that medicines are dangerous or ineffective".
- The Department of Health has argued that drugs marked as "less suitable" might have a use for a few patients. GPs could use the BNF symbols as "health warnings" and consider alternatives.

Guardian 27 October, More details on www.socialaudit.org.uk

Surgeons tighten self-regulation

Days after the Institute of Health Service Management called for NHS managers to be given powers to sack poorly performing doctors more easily, the Senate of Surgery (which represents the surgical royal colleges and professional associations) proposed measures to deal with sub-standard clinical performance while keeping regulation firmly in the hands of the medical profession.

The main proposals from the Senate of Surgery are:

- peer review of surgeons at least every five years
- rapid response teams to investigate reports of poor clinical performance, led by senior clinicians
- more rigorous assessments of surgical trainees
- more team working
- systems to gather activity and outcome data (but not league tables for individual surgeons)

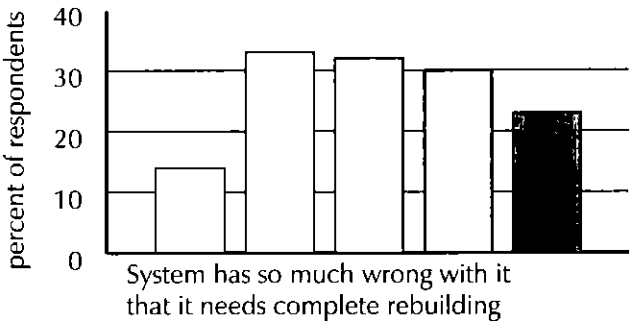
Daily Telegraph 21 October, Times 23 October, Health Service Journal 29 October, BMJ 31 October

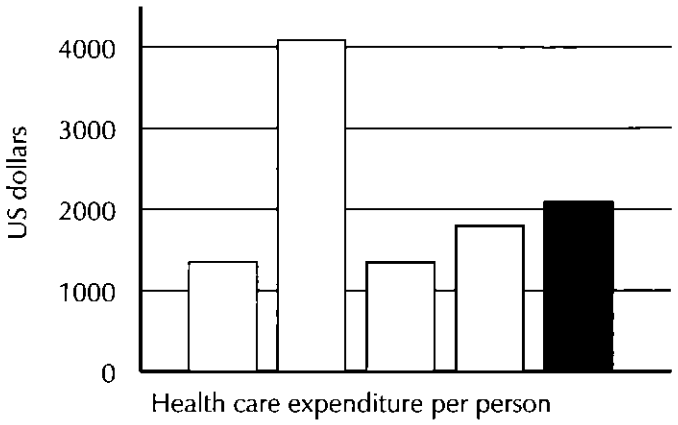
PUBLIC VIEWS OF THE NHS

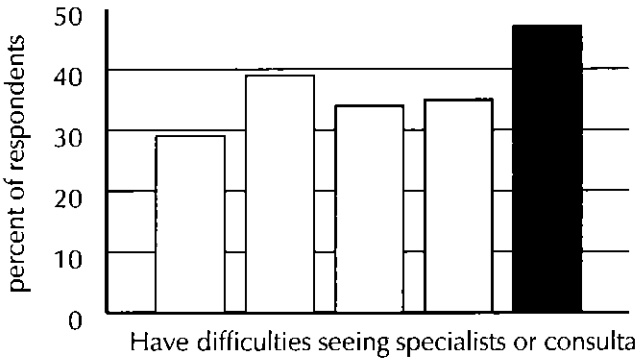
NHS tops popularity ratings

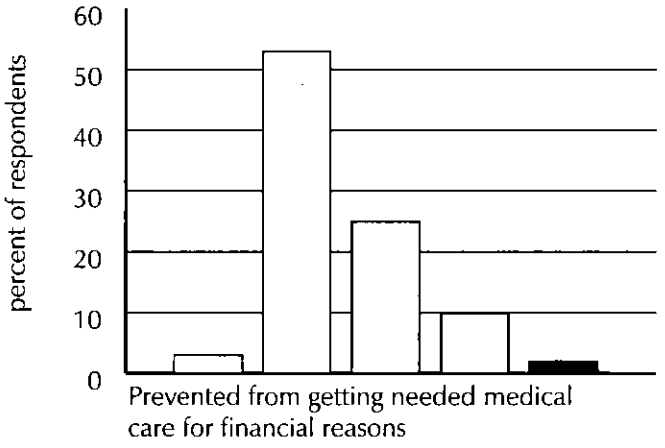
Research carried out by the Harvard University School of Public Health and the Commonwealth Fund shows just what good value the NHS is, and how popular it is compared to the health systems in four other English-speaking countries. The graphs include one on expenditure and a selection of responses from the public.

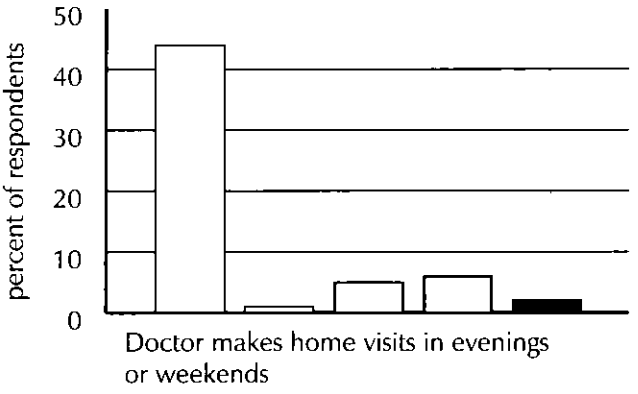
DoH press release 22 October
Pharmaceutical Journal 31 October











Service First
THE NEW CHARTER PROGRAMME

A "People's Panel" has been set up under Service First (the name of the revamped Charter Programme). Surveys and other methods are being used to consult the panel of 5000 members of the public about attitudes to public services.

The first results have now been published, and confirm the importance people attach to the NHS. Respondents were asked which four or five of 42 public services (not all public-owned) were most important to them. GPs topped the list with 47% of respondents listing them, followed by hospitals (38%), high street banks and building societies (36%) and the police (32%).

On priorities for improving the country's health, high ratings were given to access to health services, poverty, air pollution, education and unemployment, and relatively low ratings to workplaces and transport.

Summary results available from:
Service First Publication Line: 0345 22 32 42.
Full results on www.servicefirst.gov.uk/panel.htm.

A new information strategy for the NHS

As we mentioned in last month's *CHC News*, the government has launched *Information for Health: an information strategy for the modern NHS 1998–2005*. Many details are yet to be sorted out (and many pose considerable challenges), but the outline of the intended system is reasonably clear. There is more emphasis than previously on clinical, as opposed to management, information. Organisations that record patient data will automatically "push" summary information into EHRs (see box). Patient information will then be readily available to GPs and can be retrieved by others who have rights of access. If the system can be made to work, it will have benefits for patients in terms of clinicians having the information they need and of convenience, for example as electronic prescribing and booking systems become possible.

Security

Questions about security and confidentiality – both technical and political – are largely unresolved. We can expect battles over access to data between the medical profession and managers and over whether the social care sector should have access to patient records – and which parts. The strategy document does not mention patient consent to release of information (though it does briefly mention the possibility of patient-accessible records). Unfortunately, patient representatives are not mentioned in the list of "key partnerships" which are necessary to take the strategy forward.

On the technical side, the decision to go with a "data push" model (in which messages are pushed to single EHRs) rather than a "data pull" model (in which each organisation holds data which is accessed by others) reduces security problems. However, some "pulling" of data is inevitable, and the BMA and others have serious reservations over the security of the NHSnet.

Costs

The government has allocated £1 bn for the achievement of its ambitious targets. A great deal of investment is needed to develop adequate EPR systems at acute hospital level, let alone in community trusts. Estimates of the annual cost per trust range from £500,000 to as much as £3 m (largely depending on whether existing systems need to be adapted or replaced). If as many as half of all acute trusts need to replace their systems, then the cost will amount to much more than £1 bn and many existing IT projects are likely to be abandoned.

Health Service Journal 29 October, BMJ 3 October, DoH Information for Health

Full text of the strategy is available at:
www.imt4nhs.exec.nhs.uk/strategy
The NHS Confederation has produced a briefing on the new strategy. Contact 0121 471 4444, £3.50.

Key elements of the proposed system

Electronic Health Record (EHR) – a lifelong record for each patient held at the primary care team level. It will include information about patient contacts with the GP and primary care team and summary information about patient treatment by hospitals and other parts of the NHS.

Electronic Patient Record (EPR) – patient information held by local NHS organisations to support their own organisational requirements. EPR systems must be able to exchange information with others.

National Electronic Library for Health (NELH) – accredited clinical reference material available through the NHSnet for use by professionals and the public. Some material for the public will be made available nationally in part of the NELH. Local NHS organisations will need to combine this with material specific to the local delivery of care, and to make it publicly available using a variety of media.

IT moving ahead at ACHCEW

Improvements to ACHCEW's information technology moved ahead as officers of Standing Committee agreed a new investment of £14,000 to purchase a new office network which will help us to provide improved services to member CHCs. We are taking steps to ensure that it is year 2000 compliant.

Once this work is complete, the next steps will be:

- the enhanced use of email to CHCs
- a proposal for an improved website
- possible connection to the NHSnet.

ACHCEW is keen to keep abreast of IT developments whilst ensuring that money spent is invested in proven technology.

Could any CHC that hasn't informed us of its email address please contact the information team at:
achcew@compuserve.com