

CHC NEWS

ASSOCIATION OF **COMMUNITY HEALTH COUNCILS** FOR ENGLAND & WALES

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NEWS

Cancer services

Access to specialist care

Services for people with cancer are to be restructured. Announcing the plans for a new system, Dr Kenneth Calman, the Chief Medical Officer, indicated that the aim is that all cancer patients should have access to specialist care. The move has been prompted by concerns that half of cancer patients are not currently seen by a cancer specialist. At present survival rates vary across the country. A number of surveys have shown that surgeons with more experience of treating particular cancers achieve higher success rates.

Under the new system, GPs will refer patients to designated cancer units which will be established in most large district general hospitals. These units will deal with the more common cancers. Where necessary they will refer on to regional cancer centres. The regional centres will treat the less common cancers and provide technically demanding or specialised treatments. Each centre will serve a population of about a million. Dr Calman said that patients would have the right to opt for treatment at a centre rather than their local unit.

Access to information should also be improved. Dr Calman stated, "Patients, families and carers must be given clear information and help, in an easily digestible form, about treatment options." He also believes that cure rates achieved should be published.

It may take as long as five years for the plans to be implemented in full. Health ministers have given the plans their full backing, but the Treasury has yet to agree to provide money for the new centres.

Campaign on breast cancer information

A campaign, backed by the Cancer Relief Macmillan Fund, has been launched to increase understanding of breast cancer. Three million leaflets are being distributed to shops and other sites. They encourage women to ensure that a diagnosis of cancer is confirmed before they undergo surgery. Speaking at the launch of the campaign, Professor Michael Baum, professor of surgery at the Royal Marsden Hospital in London, said that some

women may be given short shrift for asking for a second opinion, but they should not be deterred by this.

A survey published by the Macmillan fund has shown that:

- ♦ four in ten patients were given an opportunity to discuss treatment options;
- ♦ six in ten patients had a discussion about surgery before giving consent;
- ♦ four in ten patients were given information about side effects.

The campaign leaflets say that women should be given a consultant diagnosis within four weeks of a GP referral. The hope is that health authorities will set this requirement in their contracts with hospitals.

Daily Telegraph 17 May, Guardian 19 May

MOTs for surgeons

Surgeons are to be required to seek recertification every five years. Recertification is to be based not only on training, but also on experience. New guidelines have been issued following concerns about the use of "keyhole" techniques by some surgeons with insufficient experience (see *CHC News* 90). The guidelines, established by the royal surgical colleges of England, Glasgow, Edinburgh and Ireland and nine associations of surgical specialists, set the following criteria for recertification:

- ♦ sufficient attendance at lectures and workshops;
- ♦ assisting in and performing enough specialist operations to maintain skills;
- ♦ having the necessary training for new procedures.

Surgeons who do not meet acceptable standards could be told to change their job or stop practising.

Professor Patrick Boulter, president of the Royal College of Surgeons of Edinburgh has said that the requirements may be made mandatory at some time in the future. The new approach will lead to more specialisation. The guidelines advise that "rare conditions and rare operations should only be treated in specialist centres".

Independent 2 June

Trust takes on community care

Community mental health services in Westminster are once again to be delivered by the NHS. Riverside Mental Health Trust has been awarded a five-year contract by Westminster Council to provide a comprehensive service. There were five other bids for the contract and there had been fears that the council might share the contract between several companies. The trust put in its bid in collaboration with the local authority's mental health team. It will take on the team's 35 staff. It is hoped that the agreed contract will enhance the continuity of care for people with mental health problems. The council is also to invite bids to provide services for elderly people.

Guardian 8 June

Judging performance

The Department of Health appears to want to follow in the footsteps of the BBC and extend performance-related pay in the public sector – in this case to doctors. While the Department gives no guidance on how such a system might work, it says that PRP should be related to the “business needs of trusts”. The chairman of the BMA's consultants' committee claims that this is shorthand for “you will comply with your managers plans for ... whatever politically motivated activity is currently in fashion”. At the annual conference of the consultants' committee, he said that the Government's proposals did not include “a single reference to patients or to standards of care”.

Guardian 10 June

Minding your Ps: Mrs Bottomley's vision

In a speech on the virtues of management in the NHS, Health Secretary Virginia Bottomley exhorted IHSM members to show the qualities of leadership. She made some strong claims. For example: the “long-standing problem [of] high-performing hospitals running out of money” had been “virtually eliminated”. And that trusts and health authorities have a “generally good financial record”. She also slipped in a possible hint of policy direction: the NHS should “not offer services when other organisations can contribute more appropriately” [our emphasis].

Channels of communication

The main purpose of the speech was to set out a “vision of the future”, structured around 4 Ps: the **P**ublic, **P**atients, **P**eople who work for the NHS and **P**artners. Mrs Bottomley's comments on the first two included many on the need for good communications. To maintain public confidence in the NHS, the public should be involved in establishing policies and priorities. Managers should inform the public and give them explanations of decisions. The public have a right to challenge decisions and be heard if they are unhappy. There were no suggestions of action to take in response to such challenges or dissatisfaction. Patients should be fully informed and involved in decisions about their health.

The press copy of the speech makes no reference to CHCs. Indeed it seems to imply

that the channel for communication with the community lies elsewhere: “The health service has put a great effort into broadening the mix of Trust and HA board members to reflect the make-up of the local community. There are now more women, more members from ethnic minorities and more local people on Trust boards and health authorities. They represent an ideal channel of communication between you and your community.” However, when Mrs Bottomley actually spoke she added some comments about CHCs. In particular, she said, “You should see the CHC as your natural ally, having contact with the wider community. You should make the CHC feel welcome, trusted and involved.”

Management costs

While defending the increase in NHS management, Mrs Bottomley also pointed to variations in management costs across the country. In some trusts, such costs come to 4% of the total pay bill; in others they come to 8.6%. DHA costs per head of population range from £2.62 to £11.82 and FHSA costs from £2.12 to £8.74. This “should give some trusts and health authorities cause for thought and action”. The Health Secretary expects “to see less bureaucracy and less paper work at every level”. She made no suggestions as to how this might be achieved within the contracting system required in the reformed NHS.

Department of Health Press Office copy of the speech

Doctors face euthanasia requests

Over half of doctors in the UK have been asked by patients to practise euthanasia and over one in ten have done so according to a survey of 312 GPs. The survey was carried out by doctors at a Cambridge health centre. Doctors were asked about "passive euthanasia" (in which a patient is allowed to die through inaction) and "active euthanasia" (in which doctors take active steps to hasten death). Doctors were asked if they would practise active euthanasia if it was legal. Almost half said they would. Of 163 doctors who said they had been asked by a patient to hasten their death 124 doctors said they had been asked for active euthanasia. Thirty-eight of these doctors said they had taken active steps to end a patient's life.

The law allows passive euthanasia since patients have the right to decline treatment. It is also legal to administer high doses of pain relief even if this will shorten life, provided the motive is pain relief. The Government has recently repeated its opposition to legalising active euthanasia.

Guardian 20 May

Health advice misses the target

The people who most need health advice are the least likely to receive it according to a report from the Office of Health Economics (OHE). An OHE survey found that people in manual and unskilled occupational groups were least likely to get health information from television, radio magazines and newspapers. They therefore rely more heavily than white collar groups on advice from their GPs. However, GPs tend to give fewer explanations to people from lower socio-economic groups. GP consultations with women from lower socio-economic groups averaged 5 minutes

compared to 7.6 minutes for women from higher socio-economic groups. (The corresponding figures for men were 5.4 and 6.7 minutes.) The report stresses that lifestyle can be changed for the better by health education, but points out that individuals need to understand the messages they receive and accept their relevance to their own lives. Doctors are sometimes discouraged from pursuing messages by what they see as a lack of response.

Health information and the consumer is available from the OHE, 12 Whitehall, London SW1A 2DY for £5.

Independent 16 May

Pharmacy staff not supervised

Pharmacists are failing to supervise staff who sell restricted medicines, according to a *Which?* report. *Which?* researchers visited 30 pharmacies and asked for pharmacy-only drugs (some of which have only recently been removed from the prescription-only list). In 27 of the shops the researchers were not asked what they wanted the medicine for or given any advice on its use. In nine shops staff did not ask the pharmacist when they sold pharmacy-only medicines. In two cases restricted medicines were sold while the pharmacist was out of the shop. This is illegal. Ten of the researchers asked for Canesten cream. Nine of them were given the cream for athlete's foot instead of the cream for thrush (the condition they were supposed to have), presumably because staff failed to ask the relevant questions. *Which?* commented that the code of ethics of the Royal Pharmaceutical Society should define supervision of assistants more clearly.

Independent 2 June

FOCUS ON ... OUT-OF-HOURS CARE

Home visits

The Government and the BMA's general medical services committee (GMSC) have struck a deal over out-of-hours cover. The Department of Health's guidance to FHSAs on the new terms of service will include the following change to paragraph 13:

- ♦ The old version states that the doctor must "Visit and treat the patient if the patient's condition so requires".
- ♦ The proposed version states, "Outside normal hours the doctor shall consider in the light of the patient's medical condition whether a consultation is needed and, if so, when."

The change requires parliamentary approval and is expected to be introduced in the autumn. The Department of Health and doctors hope that the change will result in fewer home visits. In return for the change, GPs will retain their 24-hour responsibility.

Announcing the deal, Health Minister Brian Mawhinney said that, where there is a doubt, he expects GPs to err on the side of caution. He also said that GPs must take into account the social setting of patients – for example, whether they have access to a car or have a young child whom they cannot leave alone.

The deal comes following pressure from GPs who are angry at the increasing demand for night visits. The BMA says that calls for home visits have increased fivefold in the last 25 years, and especially rapidly since the 1990 GP contract. (See *CHC News* 91 for some possible explanations of the recent rise, in addition to patient demand.)

What will the effect be?

When doctors have argued for changes to the system, they have tended to cite examples of absurd requests for home visits: to provide tampons, for example. Yet even under the old system, if they were aware of the nature of such a request when they were asked for a visit, they could have refused to make one. The visit was presumably made because the doctor wasn't sure what was going on. It is not clear how the new wording will change this. The only obvious difference, to this reader at least, is that if a doctor fails to visit after a telephone consultation and it is later shown that the visit was needed, the doctor could have a defence that s/he came to a "reasonable opinion" in deciding not to visit. How reasonable such

opinions might seem to patients is open to doubt, especially given that GPs judge that over half their out-of-hours calls are unnecessary (see *CHC News* 91). The GMSC's joint deputy chairwoman, Dr Judy Gilley, has said that BMA solicitors' advice would significantly strengthen the GP's position at service committee hearings.

ACHCEW is worried that if too many barriers are put up, patients will try to make their own diagnoses as to whether something is urgent. Some patients, especially elderly people, may be put off contacting the doctor when they need treatment.

Primary care emergency services

There are also plans to encourage the setting up of primary care emergency centres (in existing premises) where patients will be able to go out of hours. This, it is hoped, will prevent many calls for home visits when it is treatment rather than a home visit that is needed. A *BMJ* editorial acknowledges that such centres would also meet a currently unmet need for some people, for example those who find it difficult to get to their doctor during surgery hours. It then, rather inconsistently, suggests that unless access is only on referral, patients will see such centres as providing a 24-hour service rather than an emergency service. If doctors recognise that there is an unmet need for medical care, could they not adapt their services to meet that need? If GPs were to open as late as the local supermarket, say, one night a week, it is hard to believe that many people would choose unnecessarily to go to an emergency centre further from their home.

ACHCEW has the following concerns about primary care emergency centres:

- ♦ The vast majority of patients call a doctor out at night only when it is absolutely necessary. In such circumstances, these people would not normally be physically well enough to travel even a short distance.
- ♦ How will patients without their own cars get to centres late at night? Many will not be able to afford to pay for taxis even if these are available.
- ♦ How safe will centres be in the middle of the night? Is it right that the most vulnerable people may be put at risk?

Pulse/BMJ 28 May, *Independent/Guardian* 20 May

FROM THE JOURNALS

Satisfaction with GP services

Everyone must have experienced surveys in which when asked "Are you very satisfied, satisfied or not satisfied with xxx?" and you want to explain, for example, that you don't want to damn all the staff in the practice, but when you visited in March, you were treated abysmally. This survey of satisfaction at a GP practice partly gets round this problem by asking patients about their views of consultations in general, and their views of their last consultation. The results do vary between the two sets of answers. For example, 78.8% of patients feel their GPs generally spend enough time with time. This rose to 84.6% for the last consultation. Perhaps the practice has made recent improvements. Conversely, 79.4% feel they are given about the right amount of information in general, but this fell to 75.2% for the last consultation. The two sets of answers provide more reliable comparisons than could be gathered by asking the same questions of two different sets of patients on different occasions.

Many of the findings in the survey are not particularly surprising. Young people are consistently less satisfied with the GP services than older people. Women, home owners, people in non-manual social classes and those who left school aged 17 or older were all more critical than men, tenants etc.

Less predictable were the answers to a question which asked:

Do you agree or disagree with the following statement: 'Patients are able and knowledgeable enough to judge the technical/medical skills of their doctor'.

Older patients, home owners, people in social classes 1-3(non-manual) and people who left school aged 17 or over were more likely to disagree with this statement than younger patients, tenants, people in social classes 3(manual)-5, and people who left school at 16 or younger. In other words, the hardest-to-satisfy patients are more likely to believe that patients are *not* competent to judge a doctor's capabilities.

Another interesting finding is that young people are more likely than older people to believe that doctors over-prescribe. Younger people were also less willing to take medication or finish the course. While the authors appear not to welcome this scepticism on the part of young people, it could equally be taken as a healthy attitude towards reliance on medicines.

There is a rather alarming sentence in the summary of the conclusions: "Surveys and analyses of this kind ... can form the basis of a *marketing strategy* aimed at optimizing list size, *list composition* and service quality" [our emphasis]. The full conclusions, however, do not discuss how to adjust list composition. Insofar as the conclusions address "marketing" they merely suggest ways of retaining and attracting patients – by providing services they want – with a view to maximising remuneration.

British Journal of General Practice May 1994

Drug Treatments: Who should say what to whom?

The second annual Drug and Therapeutics Bulletin symposium considered the provision of information, its production and distribution and the various codes by which it is shaped. This paper summarises the discussions of: legal considerations, the patient's perspective, the hospital GP interface, information given in pharmacies, drug marketing, the media and consensus advice. As one might expect from this source, the importance of good quality information is stressed: it enables doctors to prescribe rationally and patients to take medicines from a position of understanding. Optimistically, it concludes that increasingly it will be the consumer who decides how much information is available.

Drugs and Therapeutics Bulletin, 19 May 1994

PARLIAMENTARY NEWS

The Department of Health will "shortly" be issuing for consultation draft guidance on the confidentiality, use and disclosure of NHS information, including patient records. Answering questions from shadow Health Minister Dawn Primarolo, the Under-Secretary of State for Health Tom Sackville gave some further information on what the guidance will contain.

It will advise on access by non-clinicians, including managers, to NHS patients' notes. Recipients of information should receive only those parts of the information that they need to know for their duties. The information should be anonymised unless the recipient needs to know a patient's identity. Patient information may be disclosed to agencies outside the NHS only where the patient consents or where the disclosure can be justified in the public interest or where its disclosure is required by a court

order or statute. A decision to disclose information will be the responsibility of the health service body concerned.

Computer communications comply with strict standards ensuring security and do not involve the "access by one computer to records held in another". If such access is proposed in the future "strict security guidance will be issued to control it".

Mr Sackville said there were no plans to enable patients' notes to be used in the interests of the NHS where it conflicts with the interests of patients. Information in patients' notes might be used to help in the planning and management of the NHS and with monitoring and maintaining public health. Most such functions need only anonymised data and confidentiality is "strictly maintained".

Healthcare Parliamentary Monitor, Issue 135

AROUND THE CHCs

Burnley Pendle and Rossendale CHC has invited local people who have used NHS complaints procedures to attend a conference to help them respond to proposals in the Wilson Committee report. The conference is to be held on 20 July and will be addressed by Chris Dabbs, chief officer of Salford CHC, who was a member of the Wilson Committee.


Prompted by concerns raised by **Basildon and Thurrock CHC** and some relatives of people with learning disabilities who had been residents at South Ockendon Hospital and local community homes, South Essex DHA and Thameside Community Health Care NHS Trust set up an independent inquiry. The inquiry reviewed complaints relating to six residents, the investigations into those complaints and actions taken as a result. It also considered whether the Trust's recently introduced policies and procedures are adequate. The inquiry team concluded that the CHC had behaved quite properly, and that it had facilitated rather than instigated the presentation of concerns and complaints. It also concluded that the CHC and relatives had had many legitimate concerns. Many of the 18

recommendations propose the involvement of the CHC in the Trust's procedures.

A case in Southwark has exposed a serious loophole in dental regulations. A local patient complained about incompetent dental treatment which left her in pain for almost two months. She had to take 22 days off work and paid £166 for remedial treatment from another dentist. During a formal FHSA hearing on the case the original dentist revealed that he had never filled out the NHS forms for her despite the fact that both the patient and the dentist apparently believed that the treatment was to be provided under the NHS. Since the dentist had not filled in the forms, the patient was a private patient and the FHSA had no jurisdiction. **Southwark CHC's** press release on the case has been taken up in the newspaper *Independent London*. The CHC is calling for all people seeking dental treatment to be treated as NHS patients unless they sign a form asking for private treatment. It has also called for information leaflets describing patients' rights to be available in all surgeries and for the General Dental Council to investigate and close the loophole.

After many years of campaigning, **Warrington CHC**, together with local agencies, has managed to persuade North Cheshire Health Authority to provide an improved continence service to people in residential homes. The service now includes the provision of a continence adviser to assess residents' needs and the provision of products they may need to manage their condition. Details are available from Warrington CHC.

HELP!



There must be some would-be journalists out there who would be willing to write something for the AGM newsletter at Eastbourne.

Only CHC staff and members will be able to ferret out newsworthy gossip. And it would be a great help if anyone would volunteer to write something on the guest seminar or guest speech. If you can help in any way – writing, a spell of proofreading or distributing copies – please let us know at ACHCEW.

With your help, we should be able to distribute details of most of the events during the course of the conference. Just think of not having to write up an AGM report when you get back to base!

North Thames Regional Health Authority has produced *A Guide to becoming a CHC member* in both leaflet form and on audio cassette. It explains what CHCs do, who qualifies for membership, what is expected of members, the training members receive and what people who want to be members should do. It also gives a list of all **North Thames (East) CHCs** and the names of their Chief Officers.

From the West Yorkshire Initiative:

A pilot project established by the old Yorkshire RHA is showing that, if the will exists, it really is possible to involve CHCs fully when planning health services. The "West Yorkshire Initiative" is an attempt at collaborative working between Leeds, Bradford, Wakefield and West Yorkshire DHAs. It is facilitated by a team based at the Nuffield Institute for Health, University of Leeds. The team is chaired by the head of the Nuffield Institute, Professor David Hunter.

The approach has been open from the outset, with CHC Chief Officers and Chairs being specifically targeted as key players in the process. Lesley Sterling, Chief Officer at Bradford CHC, has been seconded as a full member of the Initiative Team which has paid for an Acting Chief Officer to carry out her day-to-day CHC duties until her return. Lesley said:

"This is an amazing opportunity for CHCs in West Yorkshire. By being part of the team, I have been able to ensure that everything is in the public domain. There is a genuine wish to listen to CHC concerns and to try to resolve anxieties expressed by local people. Managers are openly sharing some of the problems they face and CHCs are helping to find a way through. Everybody is working together."

As a measure of the importance of CHCs, the Initiative financed a conference for CHC members on 6 June. The programme included Professors David Hunter and Mark Baker and explored the many outside forces which are likely to lead to major changes in the way the NHS works. The only reservation that anyone seems to have is that CHC members in West Yorkshire could end up better informed than some non-executive directors of local boards!

CHC PUBLICATIONS

GP quality assurance project

East Dorset CHC

The starting point for this project was an unsolicited request in 1989 from a GP practice in Bournemouth for the CHC to undertake a survey of the patients' views of the practice. Since then, with the help of regional funds and the, initially cautious, cooperation of GPs, 23 practices (32 surgeries) have been visited and surveyed. Over 5600 patients have responded to the surveys.

The result is a huge amount of information. The visits enabled practice arrangements to be compared. The questionnaires for patients were designed to elicit patient views on: gaining access to GPs, their reception in the surgery, the premises, facilities available and consultations. With numbers of responses from individual surgeries ranging from 98 to 288, there were enough responses to produce reliable patterns of satisfaction and dissatisfaction. The tables in the report show not only average response rates, but also ranges of response rates from different surgeries. Although individual surgeries are not identified in this report, such an approach will provide surgeries with a useful picture of how they are performing in relation to others. It also indicates how variable the need for improvements is. For example, while only 6.6% of patients overall had to wait more than 30 minutes after their appointment time, in one surgery this rose to 40.3%. Areas in which there was the biggest range of satisfaction ratings were: car parking, waiting for appointments, waiting in surgeries, health education, telephone responses, seeing own GP and being given reasons for delay (none of the surgeries scored well on the last item).

There is an excellent flow chart following a patient from the point he or she makes contact with a surgery and illustrating the satisfaction ratings (average and range) for each of the items included in the questionnaire. A clear graph gives the same information.

The conclusions to the report add an analysis of changes in survey results over time (from 1989 to 1994). It is a little more

difficult to interpret the figures here. However trends include an increase in patients aged 65 or over, reductions in referrals and prescriptions and longer waits for appointments and in surgeries.

An interesting finding is that patients using small practices with few GPs were more satisfied than those using practices with many GPs. Similarly, they prefer practices not to be decentralised into many "branch" surgeries.

The surveys appear to have been well received by the practices that took part. Some heartening examples are included of action that has since been taken at practices and of invitations for the involvement of CHC representatives in further surveys, meetings and improvements.

Burnage report

South Manchester CHC, pack of enclosures including 34-page report

In December 1993 the Mancunian Community Health Trust asked South Manchester CHC to help develop a proposal for a health centre for Burnage, an area of Manchester with greater than average need for health services. The CHC quickly set about gathering public views. It decided to hold a series of public meetings which it advertised through local newspapers, press articles, letters and telephone calls to voluntary organisations, posters and fliers.

Many of these methods served a dual purpose of raising awareness of the exercise and gathering views from a wide range of local people. The quiz for example asked people to fit into an imaginary health centre time-table 15 sessions they would like to see in a week (the resulting list is headed by baby clinics and chiropody). The quiz, which offered a £75 first prize, was accompanied by an article written by a local reporter and by details of meetings and a telephone hotline. It proved a considerable success: a tie-breaker question "I think Burnage needs a new health centre because ..." produced a wealth of varied responses.

The report outlines contributions made at two public meetings. It also presents the results of a questionnaire filled in by 35 local residents who attended a coffee morning.

Again, among this group, chiropody was rated extremely highly as an important service. This in part reflects the age of the attenders and points to an important priority for them where transport is difficult.

The CHC set up a telephone hotline using an answerphone for people unable to attend a meeting but who wanted to have a say. Their calls are presented in the report, as are additional comments received from other individuals and groups.

Advocacy at Winterton
First Annual Report on the Advocacy
Scheme at Winterton Hospital, Sedgefield

Mike Newall

Published by South West Durham CHC

The first year of the Advocacy Scheme at Winterton has been marked by some teething problems, considerable areas of success and an on-going concern about the long-term future of the scheme.

Winterton is a large psychiatric hospital which is resettling many of its residents in homes in the community. A pilot advocacy scheme managed by South West Durham CHC was funded by South West Durham DHA. It was subsequently agreed that all the DHAs with patients at the hospital would fund, on a *pro rata* basis, a two-year scheme to run until March 1995. The scheme employs an advocacy worker, a co-worker and a clerical assistant. The client group are residents of Winterton Hospital who will be resettled during the two years and/or are shortlisted for assessment for specific re-provision.

The major teething problem concerned the advisory group. At first this was multi-disciplinary, with a wide membership. However, it became distracted from addressing relevant issues by administrative deliberations. The views of its members diverged. It was decided to disband the group and set up instead a group of users, ex-users, carers and advocacy staff. Outside contacts with expert advisors were drawn on where necessary. Since August 1993 this group has met monthly and has successfully identified areas for consideration.

A separate user group was established. Certain individuals were invited to participate, but all users were welcome to

attend. It had been envisaged that the user group might develop into a Patients' Council. This proved not to be feasible partly because of the diversity of participants. The group has now stopped meeting. However, the experience of developing and supporting it proved extremely useful in devising a structure for a Patients' Council. This has now been set up. Its members include five ex-users and patient representatives from as many long-stay and acute wards as possible. It has recently held its first formal meeting with hospital managers. It intends to hold such meetings monthly.

The advocacy staff felt they had insufficient time to develop relationships with each client. To overcome this they have recruited volunteers (currently 9) who were given training which is outlined in this report. A drop-in centre at the hospital, now staffed by volunteers, is open each week and is proving popular with residents. The scheme has also been building up an information resource. Generous help from the hospital library has resulted in considerable success in this task.

A training programme to raise awareness among nursing staff was held with two groups of nurses. Some difficulties encountered with the first group led to changes which seemed to be acceptable to the second group. Regrettably, senior nursing management has refused to authorise the extension of the training for the remaining qualified nurses. The advocacy staff haven't given up though.

One important consideration is on-going contact with resettled residents, many of whom live in other districts. To this end, the scheme has been building up contacts with other organisations and particularly with the relevant CHCs. The scheme hopes to organise a conference on methods of advocacy and the future of advocacy within mental health services. It should be held later this year.

CHC publications

If you want copies of any CHC publications, could you please contact the relevant CHC direct (see directory for phone numbers) and not ACHCEW.

Discharge of elderly patients from acute wards in Worthing and Southlands hospitals back into the community
Worthing District CHC, 37 pages

A report on the findings of a questionnaire survey of 500 patients (360 returned). It covered communications with patients and relatives; transport; discharge arrangements; and help before and after discharge. The report includes summaries of in-depth interviews with 18 of the respondents.

Survey of patient opinions at Royal Berkshire Maternity Unit, March 1994
West Berkshire CHC, 10 pages

Most women responding to this survey were reasonably happy with their stay. The provision of information, as ever, posed some problems. Interestingly women in single rooms were more likely than women on the open ward to say they received the information they needed about ward rules and regulations. Women who felt they had learned enough about these rules were more likely to say that the help they received with breastfeeding and caring for their baby was good. Women in single rooms were also more likely to say that midwives' response times were good.

A report on the 13-point questionnaire in the A&E department, Northwick Park Hospital during January/February 1994
Harrow CHC, 19 pages

The CHC decided to do a quick, short survey to highlight issues for discussion with a new consultant who is to take up his post this month. The hospital has put off discussing recommendations arising from an earlier series of visits until the consultant is in post. The CHC therefore hopes to raise the new survey in its first meeting with the consultant and to move forward on previous recommendations.

Community health councils, GPs and primary care
A discussion paper by Christine Hogg and Nikki Joule, Greater London Association of CHCs, 356 Holloway Road, London N7 6PA, 33 pages

During the year-long project which led to the publication of this paper, GLACHC noticed a considerable development in CHCs' interest in primary care. However, working relationships between CHCs and GPs need improvement. The lack of rights of CHCs in relation to general practice, the pressure of time on both GPs and CHCs and the CHC role in assisting complainants have all hindered more CHC involvement in this area. The paper sets out principles for a possible framework for involving users in primary care. It recommends steps that the Department of Health, DHAs, FHSAs and CHCs could take in developing such a framework.

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East Cumbria CHC has produced three more reports in its series of quality research projects:

Privacy and dignity within Cumbria Ambulance Service: an observational study
10 pages

Accessibility of the out-patients department for people with a hearing impairment
15 pages

Accessibility of the out-patients department for people with a visual impairment (available in large print), 22 pages

The first study found that all ambulance crews showed an excellent respect for privacy and dignity. The report outlines some situations in which privacy and dignity *could* become an issue. However, during the observation week staff coped well with all such situations. The two reports on the out-patients department make a number of recommendations for improvements. The responses from the provider are included in the reports. Some of the recommendations have already been followed up, some are under consideration and some are believed by the provider to be unnecessary or infeasible.

GENERAL PUBLICATIONS

Access to medical records and reports: a practical guide

Robert Cowley for NAHAT
Published by Radcliffe Medical Press, Oxford,
176 pages, £14.95

This straightforward guide to the law and guidance concerning access to medical records and reports was written with clinical staff and health service managers in mind. It would also provide a convenient reference book for CHCs.

The book falls into two halves: the main text and lengthy appendices. The first half explains and discusses the laws relating to access. The appendices reproduce relevant statutes and health circulars and include detailed flowcharts of the processes to be followed.

The first half is itself divided into three sections. The first section covers the requirements of legislation passed in the last decade which governs access to computerised and non-computerised health records and access of third parties to medical reports. The second section covers access to medical records and reports when litigation is being considered or is under way. The final section covers professional confidence and third party access.

Rationing health care

Stephen Harrison and David J Hunter
Institute for Public Policy Research, 30-32
Southampton Street, London WC2E 7RA; phone:
071 379 9400; fax: 071 497 0373; 89 pages; £7.50

This small book is emphatically about *how* to ration rather than about *how much* to ration. In the first paragraph of the back cover blurb it states "Rationing is inevitable, but *how* should it be done?". This perspective, coming as it does from an institute "founded to provide an alternative to the free market think tanks" indicates just how far the rationing debate has shifted attention away from debate about overall levels of funding and hence the extent to which the need for rationing could be minimised.

The book looks at different methods of rationing (both explicit and non-explicit) and at who might make rationing decisions. It then considers the criteria that may be used in rationing and their appropriateness. Lastly it sets out two scenarios as options for public policy which could be used alone or in combination: local democratic representation and national health care rights.

**Spreading the word on research
or**

Patient information: how can we get it better?

Consumers for Ethics in Research and North East Thames RHA. Available from CERES, PO Box 1365, London N16 0BW, 23 pages, £2.50 (£20 for ten), £1.50 CERES members (concession limited to one copy per member)

This admirably simple booklet gives guidance on writing information for people who are asked to take part in health research. Examples of "grand prose" from existing research information leaflets make it clear just how necessary this guidance is. Careful translations of these passages into everyday English show that it is possible to get across what the readers need to know without intimidating and confusing them.

The guidance includes advice on how to write clearly and on what to include in leaflets. Some of the things to be included are obvious. Others could easily be forgotten: for example - Will taking part in the research affect social security benefits for people who might then be judged 'unavailable for work'? It also gives straightforward explanations of research methods such as "randomised trials" and "cross-over trials". It sets out answers to questions people often ask about making a decision on whether to take part.

There is also advice on the processes to follow in writing clear leaflets. This includes, for example, the suggestion that, if a leaflet is translated into another language, one person should translate the text and another person should translate it back into English.

A companion leaflet, *Medical research and YOU*, lists the questions people may want to ask about taking part in a research project. Available from CERES: single copies free; ten copies £2.50; 100 copies £15.

**Ensuring equity and quality of care for
elderly people:
the interface between geriatric medicine and
general (internal) medicine**

Royal College of Physicians of London, 11 St Andrews Place, London NW1 4LE, 33 pages

This report looks at the interface between specialist services for elderly people and other areas of hospital provision, both general and specialist. In doing so it considers acute and emergency care, rehabilitation, day hospitals

and continuing care. There are separate chapters on medical training and on commissioning. It sets out three models by which the interface may be managed: traditional (in which non-geriatricians, mainly GPs, select patients for geriatric services); age-defined (using an age cut-off for referral to geriatric services); and integrated (in which a geriatric specialist is part of a multi-consultant team).

The authors are firmer in their support for fair and equal access to acute medical services for all individuals than they are in their support for rights to continuing care. On acute care, they assert that there is no biological rationale for separating old people from the rest of the adult human race. "Thus it is difficult to set any age as a cut-off point for defining services on biological grounds". They add, however, that "local circumstances and resource constraints may provide a rationale for such an arrangement".

It is a little difficult to pin down the attitude of the authors towards continuing hospital care. On the one hand, the report takes the diminishing number of NHS hospital continuing care beds as a given, which means that "it is physically impossible to provide NHS hospital continuing care for all who might request it in preference to a private nursing home provision". The only reason the authors explicitly suggest for people stating such a preference is the reluctance of some relatives to see their parents' finances being spent on long-term care if the money would otherwise pass to them as a legacy!

On a more positive note, the report says that the informed choices of patients should predominate in discussions of arrangements for continuing care. It also recommends that health authorities should be responsible for ensuring that local GPs can provide the necessary level of care for new and existing nursing homes. It comments on the dangers of the policy of running down continuing care provision and recommends that, where local authorities intend to adopt such a policy, they should be required to follow a procedure which includes consultation. Recognising that this is a national issue, the authors call on the Government for clear guidance on a coherent policy which encompasses continuing care in both the private sector and hospital setting.

Consumer Congress Directory
A directory of organisations in the consumer movement in the UK

£5 from Congress Secretariat, c/o National Consumer Council, 20 Grosvenor Gardens, London SW1W 0DH, phone: 071 730 3469

The 13th edition of the directory lists 183 consumer members and observer members of the Consumer Congress and a gives further 20 pages of useful addresses. For each organisation, the directory gives a contact address, phone number and, in most cases, a named individual contact. The main aims, activities and services of the organisation are briefly described. One of the details listed is whether the organisation will distribute material from other organisations to its own members.

More power to our elders

Counsel and Care, Twyman House, 16 Bonny Street, London NW1 9PG; phone: 071 485 1550, fax: 071 267 6877, £6, 49 pages

This publication pulls together four papers presented at conferences and lectures over the last year. The first paper, by David Hobman, challenges the rhetoric about "choice". He looks at the availability of genuine choice for and influence by old people as consumers and through the political system. He argues that the Citizen's Charter mechanisms may have only a marginal effect for many older people. Instead he puts forward ideas about how older people could be genuinely empowered. The second paper, by Richard Hollingbery, also challenges the emphasis on "choice". Objecting to attempts to base the idea of empowerment on choice he states the obvious: "Empowerment is about power". He outlines a model in which common sense, challenge and intelligent foresight can help to achieve empowerment. The third paper, by Robin Means and Rachel Lart, is on involving older people in community care planning. It draws on a research project which has been looking at the impact of the community care reforms in four contrasting local authorities. The final paper, by Jef Smith, focuses on age discrimination and power. He concludes that empowering older people will inevitably involve a degree of disempowering those who at present have power over them – and that we would be foolish not to take this course.

OFFICIAL PUBLICATIONS

Purchasing for Health: involving local people

Examples of good practice, 30 pages and

A speech by Dr Brian Mawhinney at the National Purchasing Conference, Birmingham, April 1994, 16 pages

NHS Executive

CHCs should have received copies of the above booklets. If you need more, contact Paul Cull on 0532 545313 or at Room 4N 34A, Quarry House, Quarry Hill, Leeds LS2 7UE.

NHS day hospitals for elderly people in England

National Audit Office, HMSO, 27 pages, £6.70

CHCs have *not* received copies of this. It has been sent to all NHS trusts, which have been asked to forward details to the local CHC.

Inform '92: Meeting the information needs of disabled people in Europe

Department of Health

Presentations made at and information arising from the above exhibition and conference held in October 1992.

Copies are available from: Mrs Ann Walsh, Room 333, Department of Health, Wellington House, 133–155 Waterloo Road, London SE1 8UG, phone: 071 972 4129.

Abridged versions in large print and on tape are also available.

Quitting is Winning

Pack of promotional and information leaflets aimed at professionals and the public on giving up smoking produced by *Quitting is Winning*, an initiative endorsed by the Health Education Authority.

Information on availability from *Quitting is Winning*, Clifton House, Granville Gardens, London W5 3PA; phone/fax: 081 248 9215.

INFORMATION WANTED

Liverpool Central & Southern CHC would like to find out how other CHCs have **funded advertising for the post of Chief Officer**. Did the RHA foot the bill for both local and national advertising and, if so, in which papers/journals was the ad placed? Please contact Liz Powell at the CHC with any information.

Bill Williams, Chair of South West Surrey CHC, would like to hear of any example of local residents' fears and **anxieties about the discharge of long-stay patients** to the community being overcome by a process of education.

Enfield CHC would like to hear from any CHCs which have managed to bring about improved **standards of hospital catering**.

Shropshire CHC is seeking information about the various models used for **organising ward rounds in psychiatric hospitals** and how satisfactory these arrangements are from the perspective of users.

Wigan & Leigh CHC report that its local DHA has agreed to the **closure of an A&E unit and its substitution with a minor injuries unit** led by nurse practitioners. It is to be open for 12 hours a day. The model the DHA has been using is St Mary's at Paddington. Have any other CHCs experienced a similar change of use?

Wigan & Leigh CHC would like to contact other CHCs which have established a **Complaints Working Group**. It is particularly interested to find out what the remit of such a group might include.

As CHCs will be aware, due to a misdrafting of Regulations, certain complainants have not been permitted the **right of appeal under the FHSA complaints procedures**. (This applies to cases between April 1992 and December 1993 in which the Service Committee Chair ruled that a formal hearing was unnecessary.) Wandsworth CHC would like to know if any other CHCs are in touch with complainants who have been affected by this restriction.

North Devon CHC would like to know which districts offer either Domino or other "in-patient" **maternity services** at community hospitals.

The North Western Regional Association of CHCs' Assistants' Group, incorporating assistants from the old North West and Mersey regions and South Cumbria district, would like to hear from any other **groups of CHC assistants**.

How long has your group been formed?

How often do you meet?

What type of issues do you discuss?

Do you organise training events?

Would your members be interested in the possibility of a National Assistants' meeting?

If you have answers to any of the above, please contact: Wendy Goodwin, Assistant Chief Officer, Salford CHC.

For our files

ACHCEW would be grateful if any CHCs sending information direct to another CHC in response to a request for information could also send a copy to ACHCEW.

ACHCEW has received information and advice from a sufferer of **myalgic encephalomyelitis (ME)** who has been awarded the highest rate of **Disability Living Allowance mobility component**. Any CHCs wanting further details, please contact ACHCEW.

FROM THE VOLUNTARY SECTOR

Vitamin K supplements

The National Childbirth Trust believes that many parents are being denied their Patient's Charter rights over the administration of vitamin K to their new-born babies. The Trust has sent a report to the Department of Health raising concerns about the conflicting messages parents are being given.

The vitamin is given to some babies to promote normal blood clotting. It can be given in injected form. However, reports in 1990 and '92 showed an association between injected vitamin K and the chance of developing cancer later in childhood. As a result many hospitals switched to the oral form, which has shown no such link. After difficult deliveries the injected form is usually considered safer.

An NCT survey showed that many parents are given no information before being asked to consent to the administration of vitamin K. The oral form is not always offered, in part because vitamin K is not licensed for oral use. Policy about the route of administration differs between hospitals and GPs. There should be follow-up doses after oral administration, but some parents are not being advised of this. Confusion about the implications for breastfeeding has deterred some mothers from breastfeeding.

The NCT is calling for:

- ◆ reliable information during pregnancy to enable parents to make a choice between oral or injected vitamin K or none at all;
- ◆ careful use of language to ensure that information about the health benefits of breastfeeding is not compromised;
- ◆ consistent practice between hospital and the community;
- ◆ a properly researched vitamin K product licensed for oral use.

The report is available for £2 from Philippa Need, NCT press officer on: 081 896 1677.

Depressives Associated

Depressives Associated is trying to make itself more widely known. It is a service run by ex-depressives which aims to give information, understanding, friendship and hope to people suffering from depression and to friends and

relatives who want to help. It also aims to educate the public, cooperate with the caring professions and promote research into the causes and alleviation of depression. Information is disseminated through its quarterly magazine, *A Single Step*. The service is setting up small self-help groups, run by volunteers, in as many towns as possible. Where there is no local group, the service will put members in contact with others who live nearby (where the individuals concerned have agreed to this). It also runs a national pen-friend scheme.

Further information from: Depressives Associated, PO Box 1022, London SE1 7QB; answerphone: 081 760 0544. Please enclose 9" x 6" stamped address envelope.

A picture of children's services

Action for Sick Children is hoping to build a countrywide picture of services for children. The organisation would be grateful if CHCs could send copies of the parts of local authority community care plans that relate to children. Information should be sent to: Richard Gray, Action for Sick Children, Argyle House, 29-31 Euston Rd, London NW1 2SD.

From NCVO:

Do you know that the National Council for Voluntary Organisations produces a community care newsletter? *Impact*, published every two months, aims to inform readers about developments in community care policy and practice. It provides news, views and analysis. Occasional free supplements provide insight on topics of particular interest - recent examples include guidance on community care planning and a collection of articles from a range of perspectives entitled "One Year On".

Current readership includes voluntary organisations, local development agencies, social services departments and housing interests. The standard subscription rate is £24 p.a., with reduced rates for NCVO members and local groups. For a free copy, contact the Community Care Team, NCVO, Regent's Wharf, All Saints Street, London N1 9RL. Phone: 071 713 6161.

FORTHCOMING EVENTS

People: a force for change

- ♦ a national conference for effective voluntary and community action
- ♦ organised by Directory of Social Change
- ♦ on 22-23 September 1994
- ♦ at Church House, Westminster, London SW1
- ♦ £97.50 voluntary sector, £175 public and private sector

Further info from:

Jonathan Hardy
Conference Organiser
Directory of Social Change
Radius Works
Back Lane
London NW3 1HL
Phone: 071 435 8171
Fax: 071 794 7724

Challenging rural racism

- ♦ conference to consider research findings by the Commission for Racial Equality and the National Alliance of Women's Organisations
- ♦ organised by the Rural Team of the National Council for Voluntary Organisations
- ♦ on 21 July 1994
- ♦ at NCVO Conference Suite, see address below
- ♦ £10

Further info from:

Joy Leaver
NCVO Rural Team
Regent's Wharf
8 All Saints Street
London N1 9RL
Phone: 071 713 6161
Fax: 071 713 6300

DIRECTORY AMENDMENTS

Page 3 North Western Regional Association of CHCs

Phone: 061 833 4689 and 061 832 8183

Page 5 Grimsby CHC

Chief Officer: Philip Sturman

Page 7 West Cumbria CHC

Delete:

Patients enquiries: 0800 526 173

Page 12 City & Hackney CHC

Fax: 071 729 5943

Page 15 West Essex CHC

Chief Officer: to be advised

Fax: 0279 655863

Page 28 South Cumbria CHC

Add:

Patients Enquiries: 0800 526 173

Page 29 Tameside & Glossop CHC

Change of address:

181 Stamford Street
Ashton-under-Lyne
Lancs OL6 7PY
Phone: 061 339 3776