CHC NEWS

ASSOCIATION OF COMMUNITY HEALTH COUNCILS FOR ENGLAND & WALES

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NEWS

Complaints league table

Patients in England submitted more than 100,000 written complaints about NHS trusts in 1994-95 according to official figures.

The three trusts with the highest numbers of complaints were the Royal Hospitals Trust, East London, with 1236 written complaints; Havering Hospitals Trust, Essex, with 1062; and Forest Healthcare, Essex, with 1015. These trusts say that they top the list because of their large size. Havering and Forest Healthcare both identified problems in casualty departments as a cause of many complaints. Havering received 805 complaints which were wholly or partly about clinical care – it was the trust with by far the largest number of complaints in this category.

A few small trusts registered no written complaints in 1994-95: Dacorum and St Albans Community Trusts in Hertfordshire; Gateshead Community Trust in Tyne and Wear; Harrow Community Trust in Middlesex; Northgate and Prudhoe Community and Learning Disability Trust in Northumberland; West Dorset Mental Health and the Norfolk Ambulance Trust.

Guardian 19 January

Hysterectomies: it's where you live

Women in poorer parts of the country are more likely to be offered hysterectomies than women in richer areas according to a survey of 10,000 women who have undergone the operation.

The survey, conducted by Professor Klim McPherson of the London School of Hygiene and Tropical Medicine, found that wide variations in the hysterectomy rates by and large reflect variations in prosperity. Thus, for example, the rate in Wigan is four times that in Kensington, Chelsea and Westminster, and twice that in Norwich and Rochdale.

About 100,000 hysterectomies are performed annually by the NHS, three-quarters of them to relieve the symptoms of heavy periods. Variations in the hysterectomy rate arise, at least in part, because there is no agreed definition of a heavy period. Professor Angela Coulter, director of the King's Fund research centre, says that about half the women referred for the operation because of heavy periods do not in fact have heavy bleeding and so probably do not need surgery.

It has been suggested that hysterectomies may be offered more readily in some areas because they can be a cheaper option than alternative treatments. Wealthier women may also be more likely to question a surgeon's recommendation that they have a hysterectomy and refuse the operation.

Sunday Telegraph 28 January

New GP role

The Health Secretary, Stephen Dorrell, has announced that under a new GP contract to be drawn up next year, GPs will be expected to take on a range of services traditionally provided by hospitals.

GPs can expect "reasonable rewards" for taking on new tasks. In addition nurses working for GP practices would take on some of the GPs' current tasks such as prescribing for certain conditions and seeing regular patients with minor problems.

Mr Dorrell has said that he has an "open agenda" and wants to go ahead with the agreement of the medical profession. GPs are likely to be asked to take on increased responsibilities for providing minor accident and emergency services, mental health services and post-operative care in community hospitals or in hospital-at-home schemes. They may also work in hospitals under the supervision of consultants and provide on-going treatment for some chronic conditions under protocols designed by consultants. Mr Dorrell is to put out a consultation paper this summer and hopes to put most of the changes in place within a year. Legislation will probably be needed for some of the proposed changes.

The BMA has cautiously welcomed the suggestions, but indicated that it will link agreement to progress on GP demands for separate contracts for day and night work and to "proper funding and reward".

Times, Independent 19 January

Security in clinical information systems

The BMA has called on doctors not to develop links to the new NHS-wide computer network until the NHS adopts a security policy for clinical information. Without such a policy, says the BMA chairman Dr Sandy Macara, an NHS-wide network "would permanently destroy the individual's right to privacy and radically alter the nature of the doctor/patient relationship".

New systems – new risks

There are security risks in all health information systems. The BMA is concerned at present with the particular risks of the shared electronic patient record proposed by the NHS Executive. Potentially this will link all NHS computers in primary and secondary care, in purchasing and providing organisations, and some computers outside the NHS.

By aggregating data into large databases one simultaneously increases its value and the number of people who have access to it. Both these factors increase the likelihood that information will be improperly disclosed. In addition, the greater value of the data may bring about political pressures to legitimise access on the grounds that powerful interests (insurers for example) have a "need to know" the information.

The experience in the United States provides numerous illustrations of the risks. There, for example, a banker on a state health commission had access to a list of all patients in his state who had been diagnosed with cancer: he called in the loans of all such patients on his client list. Also in the US, a credit reference agency is currently sponsoring a bill which would facilitate disclosure of health records to interested parties without patients consent and would remove the right of patients to sue if unauthorised disclosure resulted in harm.

The BMA does not accept that information should be disclosed because of a "need to know". Instead, it says that "needs do not confer rights" and that "it is patient consent that matters".

Principles and guidelines

The BMA has published a discussion document, *Security in Clinical Information Systems*, which serves two purposes: to alert people to the threats to confidentiality in computerised systems and to present guidelines to help clinicians select suitable systems and operate them safely. It sets out principles (for both computerised and paper systems) of controlling access to records, obtaining patient consent and notifying patients of any disclosures of information. The document, which is more readable and enlightening than its dry title might suggest, has been circulated to all trusts, directly managed units and purchasing authorities. Interim guidelines have been published in a shorter form in the *BMJ* (13 January).

When all else fails – legislate

The BMA has also been taking action on other fronts. It has inspired a series of Parliamentary Questions on security policy *(Hansard 29 January col 528, 30 January col 710)*. In response, the Government stated that it has sent a networking security policy, codes of connection and a security guide to all health authorities and trusts. Further guidance on the protection and use of patient information and the secure management of computer systems is to be issued shortly. It will clarify who may have access to information and will require the NHS to inform patients about the purposes for which patient information is used.

The BMA appears to be less than convinced that official guidance will be adequate. It has drafted a Bill on the *Collection, use and disclosure of personal health information* which has been taken up by Lord Walton of Detchant. The Bill, which would make it illegal for health service bodies or health professionals to disclose health information except in specified circumstances, received its First Reading on 30 January.

Paper records and data protection

A new European directive, which confirms the general principles of the UK Data Protection Act, extends data protection to manually held records. A *BMJ* article (27 January) explains that member states have 12 years to implement the provisions for manual systems, but "active processing" of records should conform before then. Organisations will need to ensure that records conform to data protection principles such as adequacy, relevance and accuracy. The directive also establishes a right to privacy and provides for compensation for damages. Individual member states can determine what the legal sanctions will be. Until the Government legislates on the directive, the Data Protection Act remains in force.

Dentistry

NHS dentistry - a minority service?

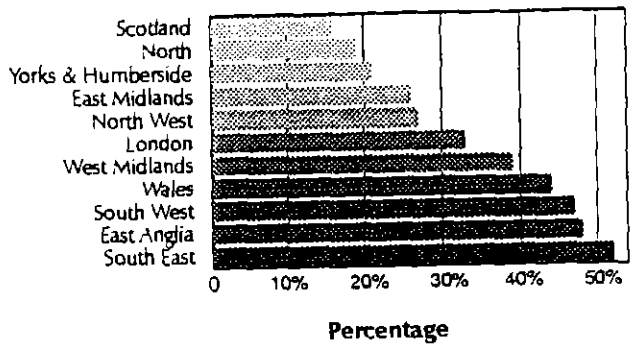
Most MPs believe that NHS dentistry will be available only for children and people on low incomes within 10 years according to a survey carried out for the British Dental Association (BDA). Another BDA-commissioned survey found that a third of people say that they are finding it difficult to register with an NHS dentist (see graph). The Association blames the situation on under-funding which, it says, is making dentists "increasingly unable to take on new patients". It is calling for a 10% increase in funding for the service in each of the next five years.

The Government denies that there is a crisis in NHS dentistry. Official figures show that 27.4 million patients are registered with an NHS dentist, up 100,000 since 1992. The number of NHS dentists has increased by 525 over the last four years to 16,000. Presumably at least part of the discrepancy between the pictures painted by the BDA and the Government can be explained by the increasing tendency of some dentists to accept only certain groups of patients for NHS dentistry, typically people on benefit or children. The two-thirds of adults who are not entitled to free treatment would not be able to register for NHS care with such "NHS dentists".

Guardian 8 January, Independent 30 January, Healthcare Parliamentary Monitor 5 February

Proportion of people reporting difficulty in finding a dentist, by region

(From a telephone survey of 1024 people commissioned by the British Dental Association)



More patients to be taken off lists

A new registration system is likely to be announced soon which will massively reduce the number of people registered for NHS dentistry. At present patients who do not visit their dentist for two years are automatically removed from NHS lists. The Department of Health has agreed in principle with the BDA that the cut-off period should be reduced to 12 months, though they are still negotiating about how the money released by this would be used. It is estimated that the change would result in 5 million patients being taken off lists.

Independent 24 January

PARLIAMENTARY NEWS

PFI in Wales

A series of Parliamentary Questions concerned Private Finance Initiative in Wales. The question-and-answer session opened with particular commendation for a car park scheme at the University Hospital of Wales in Cardiff which is to cost £6.5 million. The Government expects PFI to produce investment worth £10 million in the current financial year. Overall, there are about 20 major projects in the pipeline, worth a total of £160 million. These include:

- a £15 million cancer centre in North Wales
- a £6 million community hospital at Chepstow
- a £1.8 million day surgery unit at the Nevill Hall and District NHS trust
- radiotherapy equipment at the Velindre NHS Trust worth £4 million
- an acute psychiatric unit in Abergavenny worth £6 million

Hansard 22 January cols 4-5

Health Service Commissioners (Amendment) Bill

The Bill extending the Health Ombudsman's powers (see *CHC News* 109) has passed its third reading in the House of Commons. An amendment put during the debate, and subsequently withdrawn, concerned the lack of a mechanism whereby the Ombudsman can look at some of the wider issues of resourcing arrangements which affect patients' treatment. A Government minister said that the Ombudsman cannot look into general questions of resources, but he would be able to look at individual cases of hardship "in which he considers there might have been an unreasonable allocation of resources".

Healthcare Parliamentary Monitor Issue 165

Health helplines

The Government has provided figures on the eight main health information lines. The column on costs per call has been calculated from the figures provided by the Government in the preceding columns.

Hansard 22 January col 14

Helpline	Phone number	Calls: number	in period	Cost	Cost per call
Blood Donor Line	0345 711 711	78,516	4/95-12/95	£33,074	£0.42
Drinkline	0345 32 02 02	44,000	10/93-1/96	£516,000 (DoH funding for 1993/94-1995/96)	£11.73
Health Information Service	0800 66 55 44	1,000,788	4/92-12/95	£8,113,170 (from 4/92-3/96)	£7.60*
Health Literature Line (inc. Organ Donor Line)	0800 555 777	255,855	4/95-12/95	£108,026	£0.42
National AIDS & Drugs Helplines	AIDS:0800 567 123 Drugs:0800 77 66 00	386,953	4/95-12/95	£1,596,000 (1995/96 estimate)	£3.09*
National AIDS Helpline		4,200,514	1/90-12/94	£6,038,000	£1.44
Sexwise Helpline	0800 28 29 30	784,016	4/95-12/95	£366,854	£0.47

Note: *Calculated by reducing the total costs to take account of the shorter period in column 4.

FOCUS ON ... LONG-TERM CARE

It is likely that 40,000 people will have to sell their homes this year to pay for residential and nursing home care. The funding system clearly needs to change, but the solutions are far from obvious. Of the main political parties, only the Conservatives have been relatively clear about future policies.

Government ministers are planning legislation for the Autumn to encourage people to take out private insurance, although they are unlikely to make it compulsory. John Bowis, the Junior Health Minister, has said that people should budget to spend £30,000-£40,000 on residential or nursing home care. "For most people, that's a manageable sum out of their income – perhaps topped up by family." Well, among some circles, maybe.

However, even for the people who can afford to put money aside for old age, deciding how to do so is difficult. It is estimated that one in six people will need to enter long-term care in old age. It is therefore a tempting gamble for people to put what spare money they have into a pension, which they will almost certainly use, rather than an insurance scheme, which they probably won't need to call on.

The Labour Party has remained almost silent on the funding of long-term care. Chris Smith, the Shadow Secretary of State for Social Security, has been given until June 1996 to come up with a package of reforms to the welfare state. The party will be reluctant to propose anything that involves tax increases.

Although the Liberal Democrats have stated that they would prioritise ensuring that "the funding is available to meet the long-term health care needs of patients", they have made no statements on how they would do so.

Overall, there is a head of steam building up among "opinion formers" that some form of insurance is inevitable. This perception is in stark contrast to the attitudes of 1000 members of the public as surveyed by *Nursing Times*. Ninety-five per cent said that "elderly people have a right to be cared for by the state". Even where older people could afford to pay, 55% said that they should pay for neither residential nor nursing care. Whether these respondents would vote for tax increases is, of course, another matter.

Possible solutions

- The Institute of Public Policy Research has advocated an insurance scheme by which people could use part of the value of their home to cover care costs. For perhaps 45% of the value of a £60,000 house, a couple could guarantee cover. The house would be sold on their death, and the agreed proportion of the value passed on as an inheritance.
- A scheme floated in the last budget is the one used in New York State. Insurance covers nursing home fees for three years, after which the state picks up the bill. The Treasury might welcome this, since relatively few people live in a home for more than three years.
- Another idea mentioned in the budget is to enable people to receive a smaller occupational pension in the earlier stages of retirement in return for a larger income in later life.
- Yet another scheme would enable house-owners entering a home to sell their house and invest the capital in a trust. The interest, topped up by the state, would pay the care bill, leaving the capital intact.

Health committee report: a response, of sorts

The Government has responded to the Commons Health Committee's report on long-term care (see *CHC News* 109). The committee had called for national rather than local guidelines on eligibility criteria for NHS-funded long-term care. The DoH has said that the NHS Executive will carry out a review in 1996/97 of how eligibility criteria are operating. The review "will identify good practice and issues of concern which health authorities need to address". It is not clear how prescriptive any guidance to come out of the review will be, but "Health authorities will be required to review and revise their eligibility criteria by April 1997, taking account of national guidance."

Make do with a leaflet: The committee's call for a national Long-term Care Charter has been rejected. The Government claims that many elements of such a charter will be covered in the forthcoming local community care charters. Instead we are promised a "national leaflet on long-term care".

An unacceptable rule: People who entered nursing homes before April 1993 face being moved to another home before their fees can be met by the local authority. LAs are not allowed to top up the £295 a week income support received by these residents unless they move to another home. The DoH has avoided responding to concerns of the Health Committee about the issue, saying that it is a matter for the Department of Social Security.

Stand & deliver: making pensioners pay for care

Mary Courtney and Michael Walker for the NHS Support Federation and West Midlands Health Research Unit. Available from Fenner Brockway House, 37-39 Great Guildford Street, London SE1 0ES. Reduced price for CHCs: £7.00 (cheques payable to WMHRU & the NHS Support Federation)

All these issues, and more, are brought together in this publication which both informs and urges action. Key facts and figures are clearly presented alongside the well-signposted text.

Opening chapters outline current practice and document the retreat of the NHS from long-term care, despite the increasing care needs of elderly people. It spells out what the changes have meant in practice, for elderly people needing care and their unpaid carers. The effects include financial loss, going without care and a massive increase in anxiety about the future. Change is clearly needed to the arrangements for funding long-term care. The document sets out policy options coming from various political directions.

The publication does more than simply pull together a rather depressing catalogue of facts. A 7-page section, "What now?" gives practical suggestions on how to campaign against the erosion of long-term care services: steps to take, local facts and names to collect and questions to ask. CHCs should find this section very useful.

In this context, it is worth mentioning once again a recent National Consumer Council report which CHCs could use in advising clients on the detailed rules about charging for long-term care. *Charging consumers for social services* is available from the NCC, phone: 0171 730 3469.

Sunday Telegraph 28 January, Guardian 29 January, Independent 30 January, Healthcare Parliamentary Monitor No 165, Nursing Times 24 January

FROM THE JOURNALS

Gynaecological guinea pigs

We don't often cover articles from *Cosmopolitan,* but the magazine definitely has the advantage on some topics of not having to speak in measured academic tones. In this "shock report" it puts across its sense of outrage that medical students may examine the vaginas of anaesthetised women without the women knowing anything about it.

Doctors, nurses and midwives are expected to perform about 10 internal examinations before they can qualify. Many do these examinations on women who have knowingly consented, but others are told to examine women during gynaecological operations. One woman may be examined by as many as six or seven students.

"My god, look at it – who'd want to make love to that? Go on – she's not going to know anything about it anyway"

A consultant's words according to a medical student

"I was furious about the way this man ... had spoken about her. But I was so desperate to do well in my training that I stayed silent."

The same student

The BMA and the Department of Health have issued guidance, pointing out that women's consent must be specifically obtained. Hospitals would be wise to implement the guidance, since examinations without consent could amount to assault or battery. However, *Cosmopolitan* estimates that about half of all hospitals have failed to implement the guidelines. In some cases where "consent" is obtained, mention of examinations is hidden away in the small print of pre-operation forms. Forms rarely specify how many students may examine a patient and often imply that the woman has no choice but to comply.

There are still doctors who regard obtaining consent as "irrelevant" or "time-wasting". There is also dispute within the medical profession about whether it is more useful for students to learn through examining unconscious (and therefore physically relaxed) or conscious (and therefore responsive) patients. On balance it seems likely that both are useful. But if students do need to examine unconscious women, there is no reason why they shouldn't ask for permission. Despite some doctors' fears that women would refuse, this is not borne out by the evidence – there was only a 12% refusal rate in one survey, for example.

Cosmopolitan advises women who are having gynaecological operations to:

- ask what consent procedures are in place;
- read the consent form carefully;
- withhold consent if they wish;
- raise concerns with consultants or trust chief executives;
- or (which may be more a less daunting prospect) contact their CHC and ask about local practices.

Cosmopolitan February 1996

NEWS FROM ACHCEW

Getting the message across

Helen Richardson, ACHCEW's Press and Publicity Officer, has produced a set of **communications guidelines** to help CHCs put across messages effectively.

The guidelines give practical information and suggestions on:

- Publications
- Meeting the public
- Dealing with the media
- Writing a news release

They also give advice about things to think about before you start: what image is being created, the audience, the content of the message, how the message is to be communicated, a budget and timescale and evaluation. Copies have been circulated to CHC offices.

The future NHS – for richer, for poorer?

Some details of this year's Annual General Meeting have now been finalised. The AGM, with its theme as "The future NHS – for richer, for poorer?", will be held at:

The Harrogate International Centre
on
Tuesday 2 July – Thursday 4 July 1996

Plenary sessions

John Horam MP, Parliamentary Under Secretary of State with responsibility for CHCs, will address the conference on Tuesday afternoon.

Formal business (Annual report and Accounts etc.) will be dealt with on Wednesday morning.

Harriet Harman MP, Shadow Secretary of State for Health, will address the conference on Thursday morning.

Deadlines

Receipt of motions	Monday 11 March
Receipt of amendments	Friday 26 April
Nominations for ACHCEW's honorary officers	Friday 26 April

Offers to run fringe events, presentations or group sessions and suggestions for topics for group sessions are welcomed. Please send suggestions to Toby Harris as soon as possible.

AROUND THE CHCs

Local Voices in Bristol

Bristol & District CHC is continuing its work on Local Voices. It has recently produced a 4-page "report back" on the project. The CHC believes that Avon Health, the local health commissioner, is beginning to integrate Local Voices into the commissioning cycle. For example it has acknowledged local concerns about mixed-sex wards and crisis facilities for people with mental health problems in its *Proposals for Change for 1996/97*. Though frustrations have arisen because of the lack of a strategy to involve local people in locality commissioning, good relationships have gradually been developed. GPs on a local estate are showing an interest in developing Local Voices work. The CHC hopes to be able to help build links between GPs and local people so that they can jointly influence locality commissioning.

CHC–Trust Charter

Wandsworth CHC has formally agreed a Charter detailing its relationship with the local health provider, St George's Healthcare. It sets out basic principles underlying the relationship and outlines the CHC's rights in relation to access to the Trust premises, access to information and involvement in consultation and service planning. There is a section on media relations in which it is envisaged that, on some issues, the CHC and Trust may agree how to ensure that media coverage is not distorted by inaccurate statements from either side. In the same section, the Trust acknowledges the CHC's rights to constructively criticise and campaign about any of the Trust's services. A section on complaints states that the CHC will be represented on the Trust Complaints Monitoring Group and that the Trust will emphasise and support the CHC role in all its patient literature.

Update on Allan Sharpe's case

Chester & Ellesmere Port CHC has for some time taken an interest in prescription charges. Like many other CHCs, it has followed the case of Allan Sharpe, a pharmacist who has been disciplined for selling NHS prescribed medicines privately for less than the cost of the prescription charge. The CHC wants to pass on the information to other CHCs that Mr Sharpe has not yet been informed whether an appeal will be allowed.

Deadline

If you have items for inclusion in March's *CHC News* could you please get them to ACHCEW by 12 March.

Redefining deprivation in Dewsbury

Joy Gunter, Chief Officer of Dewsbury CHC, occasionally writes articles giving the CHC perspective for *The Health Summary*. In last month's issue, she writes of the difficulties faced by local purchasers and providers. A CHC sub-group recently praised Dewsbury Health Authority's Annual Report, but wondered how, without more money, it could be more than a paper exercise.

Funding constraints have been exacerbated by the recent reclassification of "areas of deprivation". The 1991 census excluded the question asked in earlier censuses about the ethnic origin of the head of the household. This has had a marked effect on the allocation of funding to Dewsbury, where 33% of the population is of Asian origin. Now the Department of Health classifies 36 areas of Kirklees as deprived, in comparison with 117 areas previously. Although there is transitional protection for a year, the loss of funding will be a problem in years to come. (Just in passing, Joy wonders whether these changes to classification, which are national, might not have something to do with the way they seem to benefit marginal electoral seats.)

CHC PUBLICATIONS

Mixed-sex wards: results of a survey conducted in West Kent

Sarah Mudd, Central Monitoring Unit, Joint Advisory Group, West Kent CHCs (Maidstone, Tunbridge Wells, Dartford & Gravesham and Medway) and West Kent Health Authority, 33 pages

This survey involved 195 patients in general hospital wards and 61 in mental health wards in nine trust hospitals. The results for the two types of wards showed marked differences. In the general hospitals some bays and some open wards were mixed sex, in some cases intentionally. Most of the mental health wards were mixed, but all had segregated sleeping areas (in one case segregated bays within one ward).

Patient attitudes also differed between the two groups. Only 6% of general patients preferred mixed-sex wards, compared to 43% of mental health patients. Mental health patients were much more likely to say that mixed-sex wards keep up morale. However, they were also more likely to say that mixed sex wards are less safe for women.

The survey produced interesting results because it asked many different questions about attitudes, such as questions on dignity, embarrassment, degree of preference and so on. This enables readers to see how differently worded questions elicit a different profile of response. Results from all the questions are presented in a series of coloured bar charts.

Some of the questions used the same wording as a similar survey conducted by the Patients Association. Comparative results from the two surveys are presented in a table. The Kent patients were more likely to have been informed about the type of ward and asked about preferences. On the whole they were also less likely to be dissatisfied with mixed-sex wards.

Rural healthcare survey: opinions of people in East Yorkshire's rural communities about the services they receive from the NHS

East Yorkshire CHC, 17 pages

This survey used focus group discussions and questionnaires. Concerns about dental services were repeatedly raised: difficulties of registering with an NHS dentist, the level of charges and confusion about entitlements. In all sections of the questionnaire the main problems were about getting to the services rather than the quality of services. The CHC calls for the appointment of a transport co-ordinator to make best use of available schemes and develop new ones.

Children in hospital: a survey of children's services at City Hospital, Dudley Road

West Birmingham CHC, 45 pages

The CHC sent a questionnaire to the parents of 524 child patients, and received 104 responses. There was a high rate of satisfaction among parents and children with facilities provided on wards. Children gave high praise to the hospital school and teacher, with only two out of 16 children who made a comment admitting to not liking having to do school work! Over a third of parents were not told when a doctor would visit their child on the ward, although almost all parents wanted this information.

CHC PUBLICATIONS: LISTINGS

Complaints about national health services: information pack
A plastic folder containing nine leaflets on complaints produced by the CHC and others
Clwyd South CHC

Access for disabled people: audit of premises managed by North West Anglia Healthcare Trust
North West Anglia CHC, 45 pages

Did not attends: the non-attendance of outpatients at Scunthorpe and Goole Hospitals
Scunthorpe CHC and Scunthorpe and Goole Hospitals NHS Trust, 8 pages

Investigating standards of privacy and dignity: a review of the long-stay wards at Garlands Hospital
East Cumbria CHC and North Lakeland Healthcare, 51 pages

Equal access? Problems that people with a hearing impairment may encounter while visiting Carlisle Hospitals NHS Trust,
East Cumbria CHC, Carlisle Hospitals NHS Trust and Cumbria Deaf Association, 28 pages

Equal access? Problems that people with a visual impairment may encounter while visiting Carlisle Hospitals NHS Trust
East Cumbria CHC and Carlisle Hospitals NHS Trust, 18 pages

What are the benefits of a cystic fibrosis liaison worker? A carer's perspective
East Cumbria CHC and North Lakeland Healthcare, 33 pages

Relative comfort. A survey of the elderly discharged from hospital
South West Thames Association of CHCs, 65 pages

Having your baby at North Manchester General Hospital? A survey of maternity services and the views of women giving birth at North Manchester General Hospital
Manchester North CHC, 33 pages

Manchester casualty watch: the report of a 24 hour monitoring exercise at casualty departments in five Manchester Hospitals
Manchester CHCs, 30 pages

A guide to elderly people's residential and nursing homes in the Milton Keynes area
Milton Keynes CHC, 59 pages

Transport survey, Watford General Hospital
South West Herts CHC, 21 pages

Survey of the Accident and Emergency Department of the Royal Oldham Hospital
Oldham CHC, 17 pages

Seen and still not heard?
A study of learning disability issues under the All Wales Strategy in Pembrokeshire
Pembrokeshire CHC, 97 pages

Family planning survey
Solihull CHC, 15 pages

Maternity services survey
Solihull CHC, 12 pages

Respite services one year on
Hull CHC, 4 pages

Obtaining CHC publications

If you want copies of any CHC publications, could you please contact the relevant CHC direct (details in directory) and not ACHCEW.

Consumer survey report: an investigation of nursing care
South West Surrey CHC, 29 pages

Study of children's wards in Tunbridge Wells Health District
Tunbridge Wells CHC, 12 pages

Survey of public opinion about services at the A&E Department of the Eye Hospital
West Birmingham CHC, 32 pages

Community care in Hazel Grove: a preliminary review of the medical and social services available in Hazel Grove
Stockport CHC, 9 pages

Communication in hospital. Report of the pilot study: orthopaedic out-patients department, Edith Cavell Hospital
North West Anglia CHC, 22 pages

Home Watch. A report on the registration and inspection of nursing homes in Salford
Salford CHC, 13 pages

DDH outpatients DNA survey August 1995 appertaining to the period from April 1994
Dewsbury CHC, 3 pages

Wolverhampton CHC has sent in a large batch of publications:

Environment and health and wellbeing: a focus group with representatives of tenants and residents' associations, *7 pages*

Environment and health and wellbeing: a focus group with residents of Wolverhampton, *5 pages*

Evaluating the effectiveness of discharge planning: patient satisfaction with discharge from hospital, *20 pages*

CHC citizens panel: general dental practitioners in Wolverhampton, *10 pages*

CHC citizens panel: knowledge of health services in Wolverhampton, *8 pages*

Rheumatoid-arthritis and associated conditions: a vision of future patterns of care, *3 pages*

Health and wellbeing of homeless people: focus groups with residents and staff of Fernbank Accommodation Support Project, *10 pages*

Perceptions of health and wellbeing, *approx. 70 pages*

Family doctor services in Wolverhampton: results of a survey, *approx. 50 pages*

Treatment of thyroid disorders: a focus group, *5 pages*

Going to the theatre! General surgery and urology theatre services
With the Royal Wolverhampton Hospitals NHS Trust, 4 pages

Going to the theatre! Gynaecology theatre services
With the Royal Wolverhampton Hospitals NHS Trust, 5 pages

What elderly people want: a vision workshop, *4 pages*

Language problems in pharmacies: a survey, *6 pages*

Living with epilepsy: report of a focus group with people who have epilepsy
With the British Epilepsy Association, Wolverhampton Branch, 6 pages

GENERAL PUBLICATIONS

Health information and the consumer

Papers from a symposium edited by Jane Griffin for the Office of Health Economics, 12 Whitehall, London, SW1A 2DY

The introduction to this collection of papers shows that patients overwhelmingly regard their GPs as the most important source of health information. In practice people were just as likely to get information from newspapers and magazines. This symposium, however, was mainly concerned with information provided by pharmacists and about medicines, with a few extra contributions included to broaden the discussion.

Targeting health promotion

The non-pharmacy contributions include a thoughtful paper by a GP on targeting health promotion. Peter Toon argues that too much account has been taken of risk factors and not enough of the likelihood of achieving change. The risk of smoking, for example, is greater than the risks of heavy drinking, but advice to change drinking habits is more likely to be successful than advice to stop smoking. The paper looks at how health promotion efforts can tend to raise anxiety among the "worried well", while failing to reach those who are most at risk. It suggests that efforts may need to be targeted on a middle group where the potential for success is highest.

Do pharmacists justify their role?

Pharmacists often point to their role in providing information to patients, both to supplement advice given by GPs (which patients often forget) and in relation to "pharmacy-only" and over-the-counter medicines. However, surveys have shown that pharmacists often fail to live up to their professional guidelines on information provision. Responses to these findings vary. Derek Prentice of the Consumers' Association suggests that pharmacists are proving that it does not matter who sells many medicines. If pharmacists want to keep their role in information provision, he says, they should do it better, opening longer hours and taking a pro-active role in finding new ways of getting information across to consumers.

Information leaflets

Another way in which information is being provided is through the new information leaflets which are to be included with all medicines. They will give information on ingredients, indications, contra-indications, use and storage. One of the papers in this book reviews two studies of information leaflets carried out in Southampton. The leaflets were welcomed by users, widely read and increased knowledge. Interestingly, they did not seem to increase "compliance" with taking the medicine as directed. This may be an indication that patients are empowered by more knowledge: the authors of one study judged that some patients had rationally decided to stop taking a prescribed medicine after reading the leaflet.

Getting the leaflets right

One of the Southampton studies found that about half the patients surveyed wanted short summarised points about their medicines and the other half wanted more detailed information. Leaflets could be designed to deliver both types of information.

The problems of producing leaflets for the various possible readers are considerable. In 1994 the Adult Literacy and Basic Skills Unit reported that 16% of the adult population have severe problems with reading and writing. Leaflets targeted at this group may not suit people who read easily and may want quite complex information.

In addition, leaflets written in simple English may not help many speakers of other languages. A study reported in the *British Journal of Pharmacy Practice* in 1988 found that 54% of Indian and Pakistani hospital in-patients relied on children to read the pharmacy label. This places an unacceptable burden on children, increases the risk that information is lost *en route* and leaves the patient without privacy. Leaflets in different languages may help to some extent, but a community pharmacist speaking at the symposium pointed out that many people cannot read in any language. She stressed the role pharmacists can play in getting information across, but did not say how pharmacists who speak only English can be expected to overcome language barriers. In any case, she was probably chosen to speak because she is one of the community pharmacists who *does* recognise the importance of communicating effectively with her customers.

Not at my age

Why the present breast screening system is failing women aged 65 or over

Age Concern, Mail Order Department, Astral House, 1268 London Road, London SW16 4ER; phone: 0181 679 8000; fax: 0181 679 6069; 12 pages, £3

Age Concern estimates that 2000 lives could be saved each year if routine breast screening was extended to women over the age of 65. Last month we mentioned the leaflets Age Concern has brought out to encourage older women to take up breast screening. This report provides the information to back up Age Concern's campaign.

The report documents perceptions among older women that they are not at risk and their belief that they are not eligible for screening (they are, but are not invited to sessions). The decision not to invite older women was largely based on the recommendations of the Forrest Report. *Not at my age* challenges all three of the reasons given in the Forrest Report for this conclusion, saying that they were based on little or no evidence. This report presents evidence from Sweden of deaths avoided among older women who were screened.

This BSE business

Conference report edited by Miss P Collings. The Public Health Trust, 138 Digbeth, Birmingham B5 6DR, phone 0121 643 4343; fax: 0121 643 4541, 76 pages

OFFICIAL PUBLICATIONS

Promoting clinical effectiveness: a framework for action in and through the NHS

NHS Executive. Available from the Department of Health, Storage and Despatch, PO Box 410, Wetherby LS23 7LN; phone: 01937 840 250; fax: 01937 845 381, 44 pages

This booklet is primarily aimed at chief executives in health authorities and trusts who must oversee the development of local strategies to improve clinical effectiveness. It sets out dated milestones to be reached by the NHS Executive, regional offices and health authorities. NHS trusts are not pinned down to dates: instead each of the five elements of their programme of work is optimistically labelled "ongoing".

The booklet has three main sectionst: Inform, Change and Monitor. Patients receive attention as agents of change in the second section. The document calls for information to be shared openly with the public, "especially about the agenda for clinical effectiveness". At the individual level, patients must be given good, relevant, unbiased and evidence-based information about the risks and benefits of treatment options. The Royal Colleges of Nursing and General Practitioners, the King's Fund and others are currently working on a framework for greater patient involvement in the development of clinical guidelines.

In an attempt to involve patients more in this area, the NHS Executive will be producing a version of this booklet designed for a wider public audience.

Breaking down barriers. Guidelines for purchasers of services for disabled adults aged 16-64 with physical and sensory impairments

North West Regional Health Authority

Further copies from: David M Ackroyd, Projects Manager, Community Care, North West Regional Health Authority, 930-2 Birchwood Boulevard, Millenium Park, Birchwood, Warrington WA3 7QN; phone: 01925 704236; Fax: 01925 704280. Copies are available in large print and braille.

These guidelines come in two volumes: a 19 page volume which intended to be highly focused and a 40-page companion volume which contains more information and bibliographical references.

Children and young people: substance misuse services

NHS Health Advisory Service, HMSO, 203 pages, £12

Guidelines on commissioning and providing services for children and young people who use and misuse substances.

FROM THE VOLUNTARY SECTOR

The Voices Project
Training and support for maternity service user representatives

Voices is a joint project between the Institute of Nursing Studies, the University of Hull and the National Childbirth Trust to provide training and support for representatives on maternity services liaison committees and CHCs. ACHCEW is represented on the project, which aims to increase the awareness, confidence and effectiveness of representatives and to provide them with the skills, information and resources they need to communicate with health professionals.

> "At first it was very daunting. The professionals all seemed so high powered. Now I find it really exciting being actively involved in all the changes to the local maternity services."
> *A new representative*

Objectives

- to develop and deliver two-day training courses for current and potential user representatives;
- to develop and produce a resource pack.

The project will run until May 1997. CHC and MSLC members in some pilot areas have already been sent questionnaires by the project team. If CHCs have any relevant ideas or comments, please send them to ACHCEW for input into the project or contact Voices.

For further information contact *Voices*, NCT Headquarters, Alexandra House, Oldham Terrace, Acton W3 6NH. Co-ordinators – Elisabeth Buggins on phone: 01902 631972; fax: 01902 632753 and Gillian Fletcher on phone/fax: 01737 217072.

Promoting Patient Choice

For patients to become true partners in decisions about the planning and delivery of their care they need good and timely information. The King's Fund has launched an initiative to develop information materials for shared decision-making, and believes that CHCs could make a valuable contribution to the work.

Six projects will involve patients and user groups in developing ways of putting across well-founded information about the effectiveness of care.

- The Bristol Urological Institute is developing a multimedia package outlining treatment choices for incontinence.
- A team at Hope Hospital, Manchester, will pilot a video and leaflets setting out the risks and benefits of the options for people with inflammatory bowel disease.
- Castle Hill Hospital, Hull, will produce a CD-ROM, video and leaflets for colorectal cancer patients.

These three projects will evaluate patients' responses to the materials and assess the impact of the information on patients' decisions about whether or not to have surgical treatment.

Three other projects will test the impact of information on patients' sense of control and well-being.

- Redbridge Health Care Trust is working with its health commission and a local user group to produce multi-language materials for Asian women suffering from anxiety and depression.
- Behavioural scientists at Nottingham University are producing a multimedia package presenting lively information on behavioural solutions for bedwetting by children.
- The acute pain team at the Queen's Medical Centre, Nottingham, is developing a video and leaflets for choice in post-operative pain control and will evaluate the effect of informed patient involvement on post-operative mobility.

All the projects are at a relatively early stage, and all would welcome comments or contributions from local CHCs.

For details of projects in your area and contact names, please contact Christine Farrell, Director of the Clinical Change Programme at the King's Fund on 0171 307 2673 or Alison Forbes, Press and PR Manager on 0171 307 2581.

INFORMATION WANTED

Post vasectomy syndrome

Bradford CHC believes that it has come across a national problem that is currently not being recognised.

The CHC has been contacted by a man aged 60 who had a vasectomy 20 years ago. He has recently been experiencing back pain, tenderness in the scrotal area and a dull aching in the testicles. He says that touch of any sort, and consequently sex, are now out of the question. A specialist urologist at a tertiary centre has told him that he has "post vasectomy syndrome". The syndrome develops because the body continues to manufacture sperm after the vasectomy and the sperm leaks into surrounding tissue. Over time the body becomes sensitised to the sperm leakage and painful symptoms develop. The man has been told that the only cure is removal of the testicles or castration. Castration would mean that intercourse is no longer possible - from the age of 60 onwards! The urologist seems to think that the condition is relatively common.

Bradford CHC wishes to discover how widespread this problem is, and whether there are any support groups. If you have any information on this subject, please contact the 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.

Redbridge CHC would like to hear from any CHC which has a **public information leaflet on GP fundholding** which gives the CHC perspective.

Great Yarmouth and Waverney CHC has the opportunity to include an **advertisement for the CHC** to be run as part of a video to be played in a GP's waiting room. Have any other CHCs been involved in similar exercises?

Has any CHC carried out work to find out what their members (past and present) think of being a CHC member and, in particular, **why members leave the CHC**? Hartlepool CHC would be grateful for copies of questionnaires or other information on this topic.

Oldham CHC would like to hear from any CHC which has done work on **services for people with epilepsy.**

Manchester North CHC would like to hear from any other CHCs which have had involvement with **mental health crisis services**, particularly where the developments have been user-led.

Could any CHCs with information about **"Citizens' Jury"** initiatives please let ACHCEW have details?

FORTHCOMING EVENTS

Using the "Open Government" codes of practice

- campaign seminar organised by the Campaign for Freedom of Information
- on 29 May 1996
- in London
- £20

Further info from:

Campaign for Freedom of Information
88 Old Street
London EC1V 9AX
Phone: 0171 253 2445
Fax: 0171 608 1279

The sick child at home: who cares?

- conference organised by Action for Sick Children
- for all involved in caring for children at home
- on Saturday 30 March 1996
- at Westhill College, Selly Oak, Birmingham
- full day £89; conference + 1 night's B&B £111

Further info from:

Karen Wells
Action for Sick Children
Argyle House, 29-31 Euston Road
London NW1 2SD
Phone: 0171 833 2041

Women into public life

- a day organised by Fair Play South West
- to develop opportunities for women to put themselves forward for public appointment, including CHCs
- on Saturday 16 March 1996, 10.00 a.m. to 3.00 p.m.
- at Exeter University
- £25

Further info from:
Pat McCarthy
Project Manager
Fair Play South West
Unit 5, Elizabeth House
Church Street
Liskeard, Cornwall PI14 3AG
Phone: 01579 347107

Society of CHC Staff: 1996 Training Courses

Managing CHCs

- one-week residential course for new Chief Officers
- 25-29 March 1996 organised in conjunction with the University of Surrey; or
- October 1996 in conjunction with the Nuffield Institute
- £850

Working for a CHC

- three-day residential course for new CHC staff
- 22-25 April 1996 in conjunction with the University of Central England, Birmingham

Working with complainants

- one-day course to complement ACHCEW's courses
- 14 May 1996 Nottingham
- 16 May 1996 Manchester
- 23 May 1996 London
- approx. £45

Holding the fort

- one-day course for staff who find they are usually the only one left in the office!
- 5 September 1996 Liverpool
- 12 September 1996 Guildford
- 19 September 1996 Exeter
- 26 September 1996 Exeter
- approx. £45

Further info from:
SCHCS
23 Queens Road
Barnsley S17 1AN
Phone/fax: 01226 770441

DIRECTORY AMENDMENTS

Page 8 Tower Hamlets CHC
Change of address:
Units 1&2
Albion Yard
Whitechapel
London E1 1BW
Phone: 0171 375 1555
Fax: 0171 375 0700

Page 14 Wigan & Leigh CHC
Chief Officer: Rachael Frost

Page 15 East Cumbria CHC
Fax: 01228 603134

Page 17 North Durham CHC
Phone: 0191 333 2820
Fax: 0191 333 2825

Page 25 Greenwich CHC
Chief Officer: Ms Celia Davies (delete Ms Jean Lowe)

Page 37 Coventry CHC
Change of address:
1st Floor
John Sinclair House
Canal Basin
St Nicholas Street
Coventry CV1 4LY
Phone and fax unchanged.

Page 38 Mid Staffordshire CHC
Chief Officer:
Ms Carol Renshaw
Phone: 01785 245550

Page 38 North Staffordshire CHC
Phone: 01782 744373
Fax: 01782 744417
HealthLine: 01782 410011

Page 40 Walsall CHC
Change of address:
6 St Paul's Street
Walsall
WS1 1NR
Phone and fax unchanged