

CHC NEWS

Voice of the Association of Community Health Councils for England and Wales

Nationwide Casualty Watch 2000 is the biggest yet

Over 170 CHCs in England and Wales and their equivalent organisations in Northern Ireland and Scotland visited over 230 A&E units to survey how long patients had been waiting at 4.30pm on Monday 31 January. In this, the third national Casualty Watch, more CHCs visited more A&E units than ever before.

There was huge media interest with extensive television, radio and newspaper coverage nationally (including all the national newspapers) and locally throughout the UK.

The snapshot survey showed that people are still facing unacceptably long waits even by the Department of Health's own standards.

The Royal College of Nursing surveyed nurses in charge of A&E departments at the same time to gain a better understanding of the causes of, and solutions to, long waits. These results will be published alongside the full Nationwide Casualty Watch 2000 figures featuring all CHC results in a joint report later in February.

New structures for the millennium in Wales

A new structure for Welsh CHCs was unveiled by Health and Social Services Secretary Jane Hutt on 8 February. There will be 20 CHCs, representing 26 community areas and each will belong to one of nine larger federations. The Association of Welsh CHCs has welcomed

The five longest waits revealed by the survey based on the data from CHCs that had been inputted by 11pm on 31 January and released to the press on 1 February showed:

1. A 71 year old woman with a fracture had been waiting 40 hours and 40 minutes and was on a trolley at Northwick Park Hospital, Harrow.
2. At the same A&E department a 69 year old with a heart problem had been waiting 30 hours and 31 minutes and was waiting for a bed.
3. At King George Hospital in Redbridge a 46 year old woman with abdominal pain and vomiting had been waiting 25 hours and 41 minutes and was waiting for a bed.
4. Also at King George a 73 year old man with asthma had been waiting 24 hours and 27 Minutes.
5. A 57 year old man at Redbridge with abdominal pain had been waiting 22 hours and 43 minutes and was on a trolley.

the changes, which involve three different models of CHCs and the flexibility to develop a different approach to each area, taking into account widely differing cultures, geography and populations.

More in next issue of CHC News.



Low income families paying more to use NHS Direct

Elaine Garratt, Chair of Dudley CHC will join the NHS Direct Access Issues Group after ACHCEW issued a news release and wrote to the NHS Executive about the discrepancy in call costs to NHS Direct and asked them to consider whether calls should be free at the point of use.

This issue, that effectively means some of the least well off members of society have to pay more to call NHS Direct, was initially brought to ACHCEW's attention by the West Midlands Regional Association of CHCs.

A call to NHS Direct from a domestic telephone is charged at 9p a minute. Calls from pay phones cost 14p a minute. People who use public phones are often the least well off members of society, and are also least likely to be registered with a doctor. Homeless people and travellers, who are likely to be in this situation could potentially benefit the most from NHS Direct but will have to pay higher call charges than people with their own phone.

Making a Complaint about the NHS - A Guide for Patients

A comprehensive guide for patients about the NHS complaints procedure was published in January by the independent legal charity, the Public Law Project (PLP). The guide offers patients a step-by-step review of the procedure and includes

In this issue

- ▶ Nationwide Casualty Watch 2000, page 1
- ▶ Reorganisation in Wales, page 1
- ▶ NHS Direct, page 2
- ▶ Update on the All Party Parliamentary Group on CHCs, page 3
- ▶ Launch of London Healthlink, page 4
- ▶ Medical Research Council seeks advisory group members, page 5
- ▶ On the web, page 5
- ▶ Patient confidentiality in jeopardy, page 6
- ▶ Ambulance services have duty of care, page 7
- ▶ Resources, page 8

useful advice and tips about how to get the most out of the process. The guide also gives information about other routes for redress where the complaints procedure cannot deal with a person's concerns.

The guide completes a two year programme of research into the complaints procedure undertaken by PLP with funding from the National Lottery. A full report of the research, *Cause for Complaint?* was published in September. This reported widespread dissatisfaction with the complaints procedure among complainants and those managing the process. By raising awareness of some of the difficulties people face when making a complaint and advising how these can be overcome, PLP hopes to encourage NHS organisations to review and improve their complaints handling practices.

Making a complaint about the NHS: A guide for patients is being distributed to all CHCs. Copies are free. To order, please send a 52p A4 SAE, to: the Public Law Project, Room E608, Birkbeck College, University of London, Malet Street, London WC1E 7HX.

A successful first year for the All Party Parliamentary Group

Gary Fereday, ACHCEW policy officer, writes

February 15, 1999 saw the inaugural meeting of the All Party Parliamentary Group for CHCs. This must be seen as an important development for CHCs who have not enjoyed such a Parliamentary profile before. ACHCEW provides the secretariat support and policy advice to the group to enable it to properly represent the interests of CHCs in Parliament. The group quickly grew to some 240 members making it one of the largest all party groups with an interest in health issues.

The Group's early activities were quickly taken up by the passage of the Health Bill. Members were provided with regular briefings during the passage of the Bill and issues of concern to CHCs were successfully raised in both Houses.

In May, Will Hutton, (then Editor in Chief of the Observer) addressed the group in his capacity as chair of the Commission on Representing the Public Interest in the Health Service. In response the group prepared a submission for the Commission looking at the issue from the perspective of MPs.

An Early Day Motion was tabled that congratulated CHCs on their 25th anniversary and recorded its appreciation of the work done by staff and members. Over 100 MPs signed the motion. The Prime Ministers' Agent also wrote pointing out that whilst protocol dictated that Prime Ministers do not sign Early Day Motions, Tony Blair supported the motion and that he: "would like to add his congratulations to the work that CHCs have done over the last 25 years and wishes them every success in the future"

In December the Health Minister, Gisela Stuart addressed the group outlining some of the Government's current thinking around the issue of public accountability in the health service.

It is hoped to build on this successful start and make the group even more active in 2000. ACHCEW plans to improve further its secretariat support to members, providing briefings on current issues and keeping members up to date with activities of CHCs. In this way the concerns of CHCs can be raised at the highest level.

Minister sends CHCs into Europe

The Health Minister with responsibility for CHCs, Gisela Stuart, addressed a reception on the 10 February arranged for 30 CHC members and staff as well as Department of Health officials undertaking study visits to Europe. The reception was hosted by the Chair of the All Party Parliamentary Group on CHCs, Patrick Hall MP, who also addressed the group.

The study visits are part of the "Health Care Sans Frontiers: Patients' Rights in Europe" project. This is funded by the Leonardo Fund of the European Union and backed by the World Health Organisation, the NHS Executive, ACHCEW, The Centre for Health Service Studies at the University of Kent and the King's Fund. The Minister stressed the importance of the visits, which are designed to facilitate learning between European countries around the issue of patients' rights. Ms Stuart asked the group to feed back what they learn into the debate about public involvement. The visits will take place during March to European countries including Sweden, Netherlands, Greece and Hungary.

For further information on the All Party Parliamentary Group on CHCs contact Gary Fereday, Policy Officer at ACHCEW.

Launch of new regional association of London CHCs

By Elizabeth Manero, Chair, London Health Link

On the 13th December the new regional association of London CHCs was officially launched as London Health Link.

The keynote speech was made at the launch by Minister for London, Keith Hill. Mr. Hill noted the 'vital role' which London CHCs will have with the Mayor and Assembly for London, in representing Londoners' interests in health and helping to inform the Mayor's view of health services. Contributions were also made by the authorised representatives of the three main political parties and of the Green Party, who were asked to state their party's policy on the Mayor and health.

At the end of these presentations, London Health Link issued a challenge to all the parties to use their powers of co-ordination, facilitation and collaboration with London's public sector bodies to tackle mental health services in London. Having established this contact, London Health Link will be pursuing the development of its role with the Mayor and Assembly as the May elections draw closer.

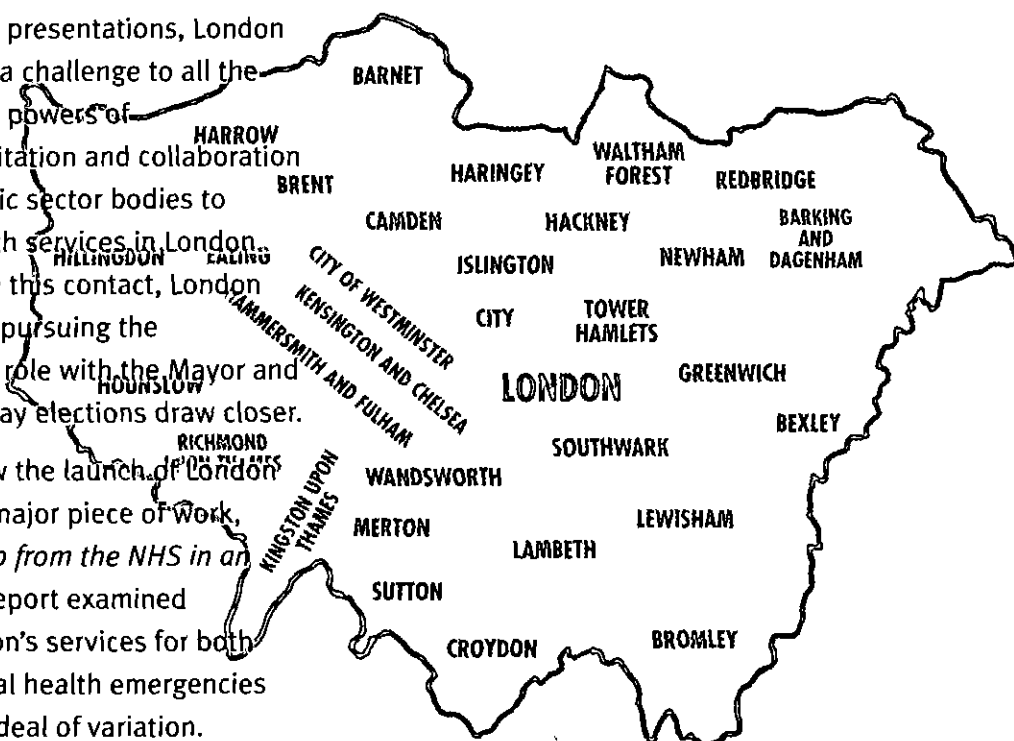
This event also saw the launch of London Health Link's first major piece of work, 'What if I need help from the NHS in an emergency'. This report examined standards in London's services for both physical and mental health emergencies and found a great deal of variation.

Contributions were made to the report by the Royal College of Psychiatrists, the

London Ambulance Service and the Metropolitan Police on their respective roles in emergency services. The Refugee Council also wrote a section describing services for this socially excluded group.

Since the establishment of London Health Link, in April last year, the London NHS Regional Office has set up formal links with the 29 London CHCs as part of the annual performance management cycle to get their perspective on the performance of the NHS in their areas. Finally, it has been accepted that judgements about the performance of the NHS are incomplete without formal input from CHCs, who really know what is happening on the ground.

Copies of the report 'What if I need help from the NHS in an emergency' (free to CHCs, otherwise £2.50) can be ordered by phoning London Health Link on 020 7609 2264.



Medical Research Council seeks advisory group members

Elizabeth Mitchell from the MRC writes

You may have noticed adverts in the national press inviting people to apply to be part of a new advisory group to the Medical Research Council (MRC). We are looking for people with an interest in health issues from a wide variety of backgrounds. The twelve people in the group will include some professional members from the scientific and health sectors.

The group will set its own agenda but we envisage that it will advise the Council on

consumer perspectives on areas such as genetics and research involving collections of human tissue and other biological samples. It will also advise on ways to promote consumer involvement.

Professor George Radda, Chief Executive of MRC, said: "We hope the Consumer Liaison Group will help close the gap between medical scientists and other people. We're keen to ensure that the group's views and concerns advise and inform the decisions taken by the Council."

We hope that CHC members will be interested in applying and in generating further interest through their extensive networks. For further information ring Nina Fletcher on 020 7670 5271 or visit the MRC web site at www.mrc.ac.uk.

On the web

Government information on the internet

A number of CHCs have asked for advice recently on how to obtain information off the internet. At ACHCEW we are increasingly downloading documents from Government sites rather than ordering hard copies.

The Department of Health site at www.doh.gov.uk has NHS press releases, Health Service Circulars and Government reports.

The UK Parliament site at

www.parliament.uk has a range of parliamentary information including select committee reports and minutes of evidence.

The central office of information website at www.coi.gov.uk has press releases from all Government departments.

The Welsh Assembly site at www.wales.gov.uk has press releases and policy documents.

If you know of a site that you think would be of interest to other CHC members or staff please email the address with a short description to helen.eldridge@achcew.org.uk.

From Marion Chester, ACHCEW Legal Officer

Patient Confidentiality - The Court of Appeal Ruling

Just before Christmas the Court of Appeal handed down its judgement in the case of R v Department of Health ex parte Source Informatics Ltd. The case concerns the confidentiality of patient data and has implications for the rights of patients to have their medical records kept confidential.

Source Informatics is a data collection company (now owed by IMSH Health an American company) which challenged guidance issued by the Department of Health (DoH) that GPs and pharmacists should not pass on patient information to commercial concerns. Source Informatics wanted to access the information pharmacists hold on doctors' prescribing habits so that they can sell that information on to companies seeking to market their own products to GPs. The information held by pharmacists is obtained from prescription forms handed to them by patients. This is a lucrative market, although Source Informatics only gives pharmacists about £150 a year for the information.

The Court held that the DoH guidance prohibiting the sale of this information by pharmacists was unlawful and that so long as the information passed on does not permit identification of the patient, it could not be challenged.

The Court heard arguments from a number of interested bodies, including the General Medical Council (GMC), the Medical Research Council and organisations

representing pharmacists and the pharmaceutical industry. The British Medical Association issued its own guidance to doctors in the run up to the hearing.

ACHCEW wanted to present arguments to the Court of Appeal on behalf of patients. However, the risk of costs being awarded against its members who are unpaid volunteers, prevented the Association from pursuing this course of action.

ACHCEW's legal officer attended the hearing. The DoH did not present the patient's case as we see it. The GMC's legal representatives did persuade the Court that the notion that patients impliedly consent to disclosure of information about them is legally unsustainable.

The Court held that the Data Protection Act and the European Directive on Data Protection do not apply to anonymised information and that patients have no interest in anonymous information about them. The Court considered that although doctors and pharmacists do owe a duty of confidentiality to patients, this duty may be limited when considering some of the uses to which information may be put. Whilst stating that patients cannot have impliedly consented to disclosures of identifiable information, they indicated that the needs of the health service might at times be such that the duty of confidentiality can be overridden.

ACHCEW is disappointed with this ruling. The Court has failed to recognise or confirm patient autonomy. Patients need to be sure that information they disclose to health professionals is not passed onto others without their knowledge or consent. Even when the information passed on is

anonymised; there are still dangers that it can be identified, either by use of codes or from their conditions, particularly where the condition or treatment involved is unusual. Further, we argue that patients may have moral or ethical concerns about the use to which their information is being put.

The DoH has asked the House of Lords for leave to appeal. Patients themselves may need to act through the courts to enforce their rights. CHCs that become aware of cases where patient confidentiality has been breached may wish to discuss this with their clients. ACHCEW's legal officer is available to provide advice where needed.

Duty of care

Court of Appeal judgement in Kent v Griffiths Roberts and the London Ambulance Service

In a recent judgement, the Court of Appeal confirmed that the London Ambulance Service (LAS) was liable to pay damages *when an ambulance arrived so late that the woman they were attending suffered a respiratory arrest with resultant brain damage.*

A doctor had called an ambulance for a pregnant woman who had an asthma attack. The ambulance service accepted the call. When the ambulance did not arrive promptly, two further calls were made.

The LAS argued that public authorities, have no legal duty to answer a call for help and could not be held liable for losses consequent upon their failure to turn up, or any delays in so doing.

The Court of Appeal decided that once the LAS accepted the call and agreed to send an ambulance out, they were under a duty of care to attend promptly. The Court confirmed that those working in the NHS have a duty of care to their patients and saw no reason why the ambulance service should be treated differently. Lord Woolf did say that the situation might be different if, due to resource problems, the ambulance service was unable to undertake to send an ambulance in response to a 999 call.

The Data Protection Act 1998

The new Data Protection Act comes into force on 1 March this year. CHCs holding information about clients and others will have to register with the Office of the Data Protection Commissioner (formerly the Data Protection Registrar). Those CHCs that have already registered under the old regime will not be required to re-register until a date three years from their original/last register entry. The Department of Health has agreed to issue detailed guidance to CHCs on their duties to comply with the Act

The main changes affecting patients, which it will introduce, concern rights of access to their health records and confidentiality. Patients applying for access to and copies of their health records will face a maximum fee of £50. Their right to confidentiality is provided for by way of data protection principles which require that all personal data is obtained and used fairly and lawfully. ACHCEW is preparing a briefing on the implications for patients of this legislation.

NHS Direct and Walk-in centres: gateways to the NHS?

**Health Perspectives, ACHCEW,
November 1999**

NHS Direct and walk-in centres are two new and radical models of primary health care which have much in common. NHS Direct is a 24 hour phone-based service, staffed by NHS nurses. Walk-in centres are open from 7 am until 10 pm, and provide treatment for minor conditions. They both reflect the Government's desire to modernise the NHS and provide faster and more convenient access to health care. They do seem to address some of the problems that have developed in out of hours care.

However, the care provided is of a limited nature, and, in the case of NHS Direct, is only advice not diagnosis or treatment. These new gateways to care should not be seen as a substitute for the full care currently provided in general practice. ACHCEW is particularly concerned about those who may be excluded from NHS Direct by lack of internet or phone access or deterred by the cost (see page 2, *Low income families paying more to use NHS Direct*). There are also issues that need to be addressed about the integration of primary care, as well as the interface of primary and secondary care.

Generic medicines: the "wild card" for PCG budgets **Health Perspectives, ACHCEW, December 1999**

The shortage of generic drugs and subsequent price rises highlight the difficulties Primary Care Groups (PCGs) currently face when attempting to balance their budgets. The problem of rising costs of generic drugs was raised in September 1999 when it was reported that the price of some commonly prescribed generics had risen dramatically with some rises as great as 800%. Furthermore some PCGs were reported as cancelling investment in new

services as a result of these rises. In response the Government adjusted this year's allocations to English Health Authorities to include an additional £90 million especially for the increased cost of generic drugs. Additional money was also found for Scotland but not for Wales.

This Health Perspective examines the issues surrounding the pricing of generic drugs sold to the NHS; the recent rise of generic prices; and the effect of such rises on the new unified budgets of PCGs. It concludes that the volatility of the prices of generic drugs poses a "wild card" for PCG budgets and may even result in the failure of plans for changes to the way that services are delivered.

New Health Perspectives are sent free of charge to member CHCs. One copy is sent for each CHC member. Otherwise they are £1 to member CHCs and £2 to others. To order send a cheque made payable to ACHCEW.

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CHC News is published ten times a year and is free to member CHCs and £50 for an annual subscription.

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