CHC NEWS

A newsletter for community health council members and staff

Hungry in Hospital – more evidence

The Alzheimer's Disease Society has produced evidence which backs up ACHCEW's claims that some hospital patients are going hungry because they do not receive enough help with eating. The Society has compiled a dossier of complaints. Examples include food being in wrappers which patients can't remove, staff not noticing that food has been dropped on the floor and staff taking away uneaten food without following the matter up. The Society believes that specialist nurses should look after people with dementia. It is also discussing with the Royal College of Physicians ways of improving the training of hospital staff in helping these patients.

Independent 25 February

Nurses hired to spy on patients

Two nurses have complained to their professional body, the UKCC, after being asked by insurance companies secretly to find out about the medical condition of patients, and to report back to the companies concerned. One nurse was offered £12 an hour to test a patient's blood for HIV – she was to tell the patient that blood was needed for "routine tests". Another nurse was asked to wear a concealed camera in order to film a man on a home visit. The insurance company believed that the man was faking an industrial injury.

Any nurses found carrying out such secret surveillance would be struck off the professional register. However, there is evidence that these are not isolated cases. A financial adviser for Massow Associates, which has many homosexual men as clients, has received complaints from men who have been (illegally) tested for HIV without their knowledge. There have even been cases of men being told over the phone, by the insurance company, that they are HIV positive.

Sunday Telegraph 9 February

Trusts forced to close

Two NHS trusts are to close down following pressure from their health authorities for mergers of local trusts.

The Anglian Harbours Trust, which provides community and mental health services, is to be dissolved within six months. The move comes after decisions by the East Norfolk and Suffolk Health Authorities to transfer contracts worth £30 million to two other trusts in order to save £1 million in management costs.

Health authority pressure on trusts to save management costs is also responsible for the forthcoming closure of Rugby Trust. The trust's management will be taken over by Walsgrave Hospitals Trust and North Warwickshire Trust. Warwickshire Health Authority has been calling for the number of trusts in the county to be reduced from seven to three in order to save £2 million from the £13 million management costs of local providers.

The changes in both areas will involve a reduction in senior management posts, but the effects on services are not yet clear. In Warwickshire, there will be a review of clinical services offered by the three trusts involved which is expected to identify services which are "no longer viable" in the next three months. In the longer term, some departments are likely to be merged to create a larger consultant base.

Times 16 February, Health Service Journal 27 February

ISSUE 9, APRIL 1997

In this issue:

ASSOCIATION OF COMMUNITY HEALTH COUNCILS FOR ENGLAND & WALES
Earlsmead House, 30 Drayton Park, London N5 1PB. Phone: 0171 609 8405 Fax: 0171 700 1152

Reviews at Ashworth and Broadmoor

Allegations of paedophilia and pornography

Less than five years ago a judicial inquiry published a damning report on the oppressive regime at Ashworth Hospital, one of England's three top security hospitals. Reforms were introduced, and last year the Health Advisory Services reported that major advances had been achieved at Ashworth. However, early this year shocking allegations and evidence emerged suggesting that things are far from well at the hospital.

Last October Stephen Daggett, a patient who had absconded and returned to the hospital, made serious allegations including some about paedophile activity and pornography within the hospital. On 17 January a search of the ward in which Mr Daggett had stayed uncovered a large amount of pornographic material. Two weeks later the police visited the home of a former patient and a child was taken into emergency care.

It is clear from the Department of Health press release that the Secretary of State for Health, Stephen Dorrell, is angry that as late as 17 January senior managers maintained that there was no foundation to press reports about problems at the hospital. It appears that a health minister had questioned the hospital on the issue last October. On 7 February Mr Dorrell set up a statutory inquiry to review the policy management and clinical care of the Personality Disorder Unit at Ashworth under the chairmanship of a recently retired judge, Peter Fallon QC. The inquiry report will be published. The Chief Executive of Ashworth Hospital, two nurses and a psychiatrist have been suspended.

The Acting Chief Executive at the Hospital has banned visits by children to wards. Visits by children will be supervised and pre-arranged. Visitors will not be allowed to walk around the grounds unescorted and former patients are barred.

Too much patient power?

There is also to be a review of security and patient care at Broadmoor Hospital following concerns raised by the Prison Officers' Association. Among the Association's complaints were that patients are intimidating staff and there are too few experienced nurses. A particular complaint is that the management has "gone over the top" with the patients' council, so that now patients have too much influence. However, the vice-president of the patients' council says that the council cannot influence important management decisions and a spokesman for the hospital said that it has no power – it is merely a forum to voice patients' views. The Regional Director of Anglia and Oxford Regional Office has been asked to report by the end of March.

DoH press releases 7 February and 3 March, Guardian 8 February and 3 March, Times 11 February

Absenteeism among detained patients

Unannounced visits by mental health commissioners to hospital psychiatric units revealed that 32 detained patients were absent without leave. Staff considered 11 of these patients to be potentially violent. The visits to 309 wards, providing for a total of 6361 patients, took place last November.

Some wards were under great pressure. While an average of 86% of the beds were occupied, 8% of wards had more patients than beds. Although most wards had policies on the safety of women patients, 71 women (3%) were sharing sleeping areas with men.

Daily Telegraph 4 March

Survey on the ethics of screening

The Nuffield Council on Bioethics is to conduct a survey to find out what members of the public think about genetic screening for mental disorders. Genetic links have been identified for some conditions such as schizophrenia and depression.

The ethics of how to handle the results of genetic tests are difficult enough for conditions in which a test gives a clear indication that someone will get a disease. A positive test for the gene that causes Huntington's chorea, for example, indicates that later in life the individual can definitely expect to suffer from the disease. This raises issues about how insurance companies, and others, deal with people who are healthy at present but may have problems in years to come. It also raises ethical issues about the value to individuals and their families of knowing about problems in their future lives.

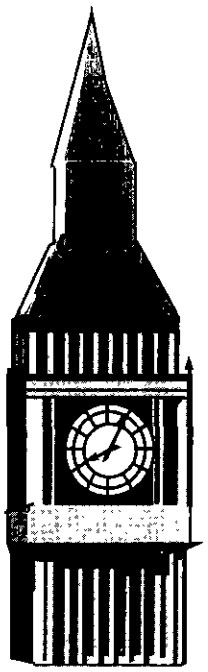
Tests which have "low penetration" (i.e. which are poor at predicting how likely someone is to develop a condition or to what extent) raise a new set of problems. Insurance companies may give them more weight than they deserve on scientific evidence. As one geneticist points out "we are all carriers of some good genes and some bad genes". Tests identify only the small minority who are at some (undefined) risk from disorders that can be tested for directly.

The survey is to include questions about:

- how genetic information should be used by insurance companies;
- how healthy individuals will cope with tests suggesting that they have an increased risk of mental disease; and
- the implications of tests for disorders with low penetration.

Daily Telegraph, 21 February

HEALTH SERVICES FOR CHILDREN



Reports of the House of Commons Health Committee
The Specific Health Needs of Children and Young People
Session 1996/97 Second Report, £11.50, The Stationery Office
Health Services for Children and Young People in the Community
Session 1996/97 Third Report, £13.60, The Stationery Office

The House of Commons Health Committee has been anxious to publish its reports on the health of children and young people before the dissolution of Parliament. As a result these two initial reports raise issues which the Committee are anxious to publicise, but do not cover a full range of health needs or health services. In particular, they say little about routine screening, health promotion and preventive work. The report on Specific Health Needs gives an epidemiological overview, with details of mortality, illness and disability. The report on Health Services in the Community deals with services in the home and at school. Here we pick out a few of the issues highlighted by the Committee.

Not enough information

The overall epidemiological picture was encouraging, with improvements in mortality and illnesses. However, a good deal of information needed for planning and commissioning is lacking. The Committee was surprised to hear from Department of Health that there is "no readily accessible data on variations in child health by region and social class". There is inadequate data collection and research on accident prevention. The DoH could not provide figures on the total number of school nurses and the school nurse:school ratio. The Committee comments that even if data of this kind is not collated centrally as a matter of routine, there should be mechanisms which could provide it at short notice. Otherwise "it is difficult to see how central monitoring of local decision-making can be effective".

Astonishment over medicines

The Committee was "astonished" at the situation in regard to medicines for children. It found that doctors are having to guess the appropriate dosages of many medicines when prescribing them for children. The situation arises because licences for medicines are granted before the medicines have been tested adequately, if at all, in children. Many medicines are administered by a route, in a formulation or in a dosage which has not been approved by the Medicines Control Agency. Some, such vitamin K, are not even licensed for human administration at all. The Committee urges the DoH to take urgent action.

Hands on care at school

In considering the school health service, the Committee focused on the need of some children for "hands on" care. These needs are increasing with the trend for children with special needs to enter mainstream rather than special schools. Official guidance is vague and the existing School Health Service does not allow for a clear NHS input into hands on care. The National Association of Head Teachers suggested that parents might be expected to come into school to look after their children, even for something as simple as ensuring that a child takes medication at the right time. The Committee believes that this is unacceptable. There should be, it says, a recognition as a matter of principle that a certain level of service should be provided to pupils who need it. Schools should be required to make such a service available. Care could be given, as appropriate, by teachers acting *in loco parentis*, by specially trained teachers and by school nurses. There are problems of legal liability, but, the Committee argues, these can be overcome. The NHS might be able to indemnify the non-formal carers involved.

Sections of the House of Commons report on community services echo almost point for point shortcomings identified by Bristol & District CHC in *Forgotten Families*. CHC Members held meetings with a wide range of groups, locally and in other areas, to identify the expertise available, services covered and criteria for giving support. They have produced an interesting report. Like the Health Committee report, it speaks of the fragmentation of services, the lack of trained community children's nurses, the need for 24 hour cover by such nurses, variations in provision across the country and the need for appropriate equipment.

Forgotten Families: Health services for children with severe disability/illness living in the community, Bristol & District CHC

SOME RECENT PUBLICATIONS

Election 97:
Information for owners, managers, staff and residents of residential care and nursing homes
Counsel and Care, Twyman House, 16 Bonny Street, London NW1 9PG; phone: 0171 485 1550
Available free. Send an A4 SAE (26p stamp).

This briefing paper identifies practical steps which can ensure that residents are able to vote. The deadline for postal/proxy vote applications is 11 April with some exceptions in cases of unexpected illness.

A report on NHS Abortion Services
Abortion Law Reform Association
11-13 Charlotte Street, London W1P 1HD; £5.

There is more statistical information available on termination of pregnancy than on any other health treatment. This report presents statistics available from the Department of Health and the results of a survey on abortion services provided by all 108 HAs in England and Wales. The survey focused on budgets, contracts and access to services.

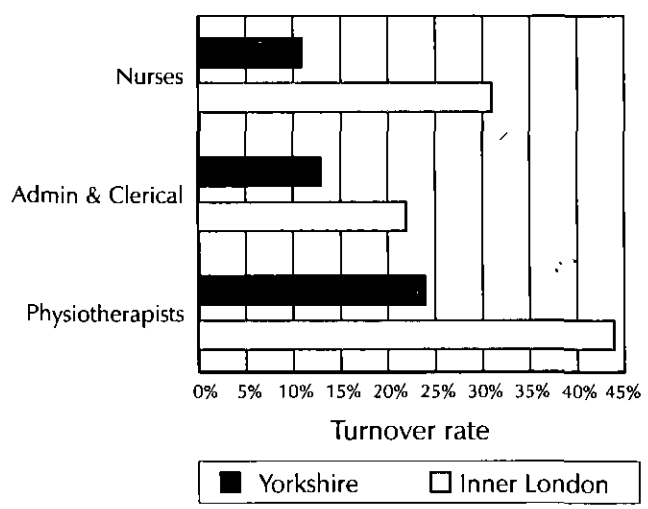
About 70% of abortions in England and Wales are funded by the NHS, with some HAs funding over 90% while some fund fewer than 50%. The report examines reasons for the variations (very often the attitude of senior staff) and how access is restricted. Many health authorities and GPs were found to be applying an unofficial means test on women requesting abortions, steering those who are able to pay towards private provision. This makes abortion the only clinical procedure where the patient's ability to pay is regularly used to exclude them from NHS treatment.

Some health authorities have recently increased the availability of NHS-funded abortions for various reasons including public pressure, needs assessment, appointment of new staff and HA mergers. The Abortion Law Reform Association intends to investigate what action may be taken in other areas to increase the proportion of abortions funded by the NHS.

Finders, Keepers:
The management of staff turnover in NHS trusts
Audit Commission, Bookpoint Ltd, 39 Milton Park, Abingdon, Oxon OX14 4TD; phone: 0800 502030, £10.

This report deals with a growing problem in the NHS. Turnover of staff is increasing, and can be costly in financial terms and in terms of service standards, although very low turnover also has its downside. The Audit Commission gives advice on what trusts can and cannot expect to do in tackling the issue. There will always be variations between regions and between staff groups with, for example, inner city areas finding it harder to retain staff than rural areas. As with all Audit Commission reports, the factors involved are set out in graphs and diagrams, making them easy to understand.

Variations in staff turnover
Turnover in two areas among three staff groups
Source: Finders, Keepers, Audit Commission



While national and local economic factors affect staff turnover, more than half the variation in turnover rates is explained by differences in how trusts manage their staff. The report gives advice on understanding the local situation, designing services to make best use of available skills and developing action plans on forward planning and staff management.

Social services complaints training
CHCs may be interested in the complaints procedures used in social services and social work departments. This attractive skills training manual is aimed at complaints officers. The chapters follow the various stages of a complaint, each providing discussion material, useful exercises and case studies. In addition one case study is followed throughout the manual.

A Matter for Investigation
Commissioned by the Social Services Inspectorate. The manual costs £45.23, so it would be best to get hold of a copy which has been sent to social services departments. (It is loose leaf and SSDs are free to photocopy it.) Otherwise copies are available from The EBS Trust, 36-38 Mortimer Street, London W1N 7RB.

A MISCELLANY

Future of the Changing Childbirth Implementation Team

The Changing Childbirth Implementation Team (CCIT), established in July 1994, completed its planned work on 31 March 1997. Some of the initiatives established by CCIT are being continued by a smaller national team, also funded by the Department of Health. The newsletter, *Changing Childbirth Update*, the contacts database of Changing Childbirth initiatives and the national database of maternity services liaison committees are all being maintained by the new team. The team is managed by Jane Cowl, formerly CCIT's Projects Officer for Consumer Issues.

If you need information or advice on a Changing Childbirth issue, or would like to tell the team about an initiative you are involved in, please contact the team at this new address:

Changing Childbirth Team
Health Care & Public Health Directorate
NHS Executive Anglia & Oxford
6-12 Capital Drive, Linford Wood
Milton Keynes, MK14 6QP
Phone: 01908 844400

Schizophrenia Association of Great Britain

The SAGB offers information and advice about schizophrenia. Recently it has been using a Lottery grant to raise awareness and increase people's understanding of the condition. It has produced various booklets and leaflets including *A Beginner's Booklet about Schizophrenia*, which is aimed at young people. The booklet describes the symptoms of schizophrenia in simple terms and gives some basic initial advice on what to do. It stresses that many manifestations of schizophrenia can be treated or cured with minimal doses of medication and careful attention to diet.

The SAGB also produces a newsletter. The February issue includes a long article which is highly critical of modern psychiatry. It argues that many psychiatric symptoms are caused by diseases in the body and calls for a medical approach that recognises the influence of biochemical and nutritional factors on the brain.

SAGB membership costs £5.
For more information contact: SAGB, Bryn Hyfryd, The Crescent, Bangor, Gwynedd, LL57 2AG.
Phone and fax: 01248 354048.

Publicity for Self Help Groups

We have been approached by the National Cancer Self Help Awareness Committee which aims to publicise the Self Help Movement so that all those who may benefit are aware of its existence and accessibility. The committee is keen to find out whether cancer centres and units are in practice encouraging and publicising self help groups. If they are not, then the committee's case for more publicity will be strengthened.

CHCs could help by answering two questions:

1 Do their local cancer hospital(s) encourage local Self Help Groups?
2 Do their cancer hospital(s) have links with the Voluntary Cancer Care Sector?

Please send your answers to:
Dr E J Watts
CancerLink, c/o 11 Park Way
Brentwood, Essex, CM15 8LH

Elder Abuse Response Line

Action on Elder Abuse has been piloting a response line for anyone who is concerned about the abuse of an older person. The confidential service offers information and support in three languages: Hindi, Urdu and English. The service is continuing at the following times:

2.00 p.m. to 4.30 p.m.
Monday to Friday

on
0181 679 7074

For publicity cards giving information about the response line contact: Action on Elder Abuse, Astral House, 1268 London Road, SW16 4ER.

Charter Mark Awards

CHC Chief Offices have been sent details of the 1997 Charter Mark awards scheme. A number of CHCs have won the award or been highly commended during the last five years, so why not apply this year? CHCs are also in a very good position to know about other NHS services in their areas. You could nominate any particularly good services for a Charter Mark award.

Application for support with legal costs

Barnet Health Authority carried out consultation exercises about the future of Barnet and Edgware Hospitals and then published its plans which included a PFI deal. However, just before Christmas 1996 the health authority announced that it would be departing from those plans and intended to close down Edgware Hospital before the new Barnet Hospital was completed – and even before the funding for the deal had been approved. Barnet CHC expressed its concerns about the changed plans, which would have the effect of leaving a gap in health care provision. It pointed out the risk that the community could be left with only a half-completed hospital if Edgware was closed before the funding of the second phase of Barnet Hospital was assured. The health authority failed to pay heed to these warnings and the CHC decided to seek legal advice.

ACHCEW's legal officer advised the CHC that it could require the health authority to re-consult on the new proposals as they differed significantly from those which had formed the basis of the previous consultation. It was also suggested that the CHC and local community might ask the courts to enforce their legitimate expectation that services would not be closed at Edgware until alternative provision was available. This expectation had arisen partly as a result of promises to this effect made to Parliament by the former Secretary of State for Health.

Barnet CHC applied to the NHS Executive for support with the costs of obtaining a barrister's opinion on the merits of its case. (This opinion was favourable.) The CHC then asked for help with the costs of making an application for leave for judicial review in the High Court. Both applications were supported by ACHCEW's legal officer. The application was only partly successful. On 17 February the NHS Executive agreed that it would meet the barrister's fees. This was more than four weeks after the request and after the CHC had actually incurred the costs of obtaining the opinion. However, the NHS Executive failed to deal with the CHC's request for support with the costs of mounting a legal challenge and thus effectively prevented the CHC from enforcing its rights in court.

The prospect of personal liability for the costs of bringing legal proceedings has deterred CHC members from using the courts. ACHCEW is firmly committed to pursuing this matter to ensure that funding is made available to CHCs when needed to allow them to make and defend legal challenges to uphold their rights and those of their local communities.

Marion Chester, Legal Officer

Patients' Agenda Conference

On 25 February ACHCEW held a conference on The Patients' Agenda. Representatives from CHCs, trusts and health authorities across the country came to discuss the issues in workshops and to hear speeches from Toby Harris; Chris Smith, the Shadow Secretary of State for Health; Denise Platt, head of Social Services at the Local Government Association; and Stephen Dorrell, the Secretary of State for Health.

Stephen Dorrell gave a brief address welcoming the publication of the Patients' Agenda and acknowledging the role of CHCs in monitoring the NHS. He agreed with the main areas covered by the Patients' Agenda, but said that he did not agree with all the specific proposals in the document. He emphasised that the recent White Paper, *A Service with Ambitions,* stresses the importance of giving patients more information and choice.

Chris Smith outlined proposals for giving us all a real say in the NHS at the levels of individual treatment; services for defined health groups; and the running of the NHS. Having pointed to the possible conflict between CHCs being involved in discussions with purchasers and their role as patients' advocates, he said that CHCs should not give up their patient advocacy role *and* that they should have a real input into the strategic planning of the health authority.

GORLIN SYNDROME

The Gorlin Syndrome Group has asked us to bring its work to the attention of CHCs. The syndrome, also known as Naevoid Basal Cell Carcinoma, is a hereditary condition which can affect various organs. There are three common symptoms: skin cancers, cysts of the jaw and pits on the palms and soles of the feet. There are other, less common, complications. It can affect both children and adults.

The support group aims to:

- offer support through a group helpline, newsletters, meetings and contact with other affected people and medical professionals;
- provide information about the syndrome, how to cope, treatments and medical advances;
- increase awareness and educate individuals, professionals and the public.

For more information contact: Gorlin Syndrome Group, c/o Mr Jim Costello, 11 Blackberry Way, Penwortham, Preston, Lancs PR1 9LQ; phone: 01772 496849.

DELAYS IN GETTING HOME: CHC REPORTS

Discharge delays

Despite the emphasis on discharge procedures in recent years, the Royal United Hospital Bath NHS Trust appears to have no protocol for dealing with patients on the actual day they are discharged. This survey identified some relatively simple measures which could be taken to minimise delays and could be incorporated into a hospital-wide discharge protocol.

Ward sisters were interviewed to find out about procedures, the extent of delays and reasons for them. The main problem areas were:

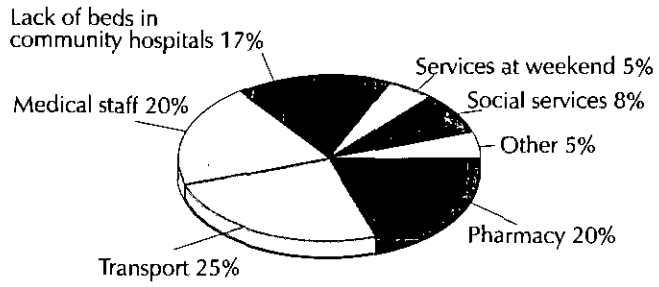
- *the need to give 24 or 48 hours notice for* hospital transport;
- delays in getting take-home medicines from the pharmacy; and
- timing of ward rounds, delays in getting letters to GPs from hospital doctors and delays in writing prescriptions.

One finding is that delays have a knock-on effect, especially on the transport service. Ambulances may be kept waiting while a patient waits for medicines, for example, and the delay can build up if this happens with several patients. The Ambulance Liaison Officer was also annoyed that wards often fail to notify the service when plans to discharge a patient are cancelled.

Reasons for delays in discharge

Services identified by nurses as causes of delay

Source: Bath & District CHC



While it may be difficult to avoid delays with discharges arranged at short-notice, there is little excuse for not having letters and drugs in place when a discharge has been planned in advance. The trust's medical director agreed that prescriptions and discharge letters should be written up 24 hours before elective dishcarge so that everything is in place on the day.

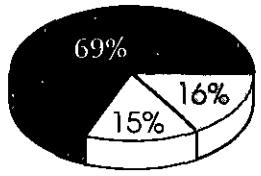
The extent and causes of delays on the day of discharge
Bath & District CHC

Patient transport

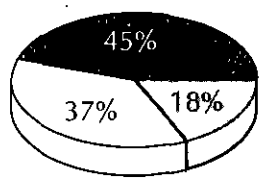
We have recently received three CHC reports on patient transport services. The graphs on the right show the differences between the three areas when it comes to getting patients home on time.

Waiting times for travelling home by hospital transport

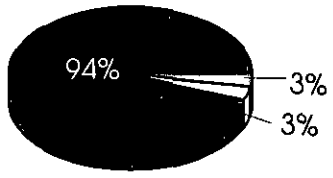
Calculated from figures given in the three CHC surveys



N Durham and S Durham & Weardale



Blackburn, Hyndburn & Ribble Valley



West Dorset

- On time or less than 30 minutes late
- 30 minutes to 1 hour late
- One hour or more late

Findings of a survey of users of patient transport services, Blackburn, Hyndburn & Ribble Valley CHC
Survey of patients' views on hospital transport services, West Dorset CHC
Survey into patient satisfaction with the outpatient passenger transport service
North Durham and South Durham and Weardale CHC

GPs and User Involvement

Choices and opportunities for user involvement in the primary care-led NHS
Greater London Association of CHCs

Working in partnership: A guide for GPs on setting up patient participation groups
West Essex CHC

The GLACHC publication reports on a study into the CHC/GP relationship in London. The study involved a telephone survey of all 30 London CHCs, in-depth interviews with staff at 10 CHCs, interviews with GPs and other practice staff.

Although in general there is not much involvement between CHCs and GPs in London (except in relation to complaints), interviewees gave many examples of how CHCs may become involved and barriers to involvement. The 20 CHCs which have some involvement with GPs identified the following activities:

Activity	Number of CHCs
Involvement in Total Purchasing Project	8
Involvement with local medical committee	8
Involvement with patient participation groups	8
Involvement in GP commissioning group	8
Some involvement in locality commissioning	5
Liaison with multifund	4
Represented at meetings of fundholders	4
Have carried out visits to practices	4
Involvement in MAAG	3
Specific work with individual practices	2
Analysis of GP fundholders' plans	1
Carrying out surveys	1

It has proved particularly difficult for CHC members to become involved in working with GPs, partly because they have no statutory framework to use. CHC chief officers commented that any work with GPs has to adopt a "softly, softly" approach, and this may not suit members who are used to acting as representatives of less powerful patients in the face of a powerful NHS. In addition, acute services may still command more immediate attention.

The CHCs which had most involvement with GPs had placed primary care high on their list of priorities for CHC activities. However, there were still many constraints, the main one being the perception among GPs that CHCs are adversaries in their complaints role. As one interviewee commented:

> "It helps if you are not seen as Satan on wheels."

Many suggestions are given on how CHCs can improve relationships, though at best it is a slow process. Working on focused projects and on issues of mutual concern tended to produce the best results. Other suggestions included sending CHC newsletters to GPs, writing in other newsletters sent to GPs and starting the process by working with the GPs who are most receptive.

West Essex CHC has produced a folder of loose leaf sheets which act as a guide to GPs on working in partnership with patients. They include notes on ways of involving users, types of patient groups, setting up a group, keeping a group going and anticipating/overcoming difficulties. The CHC's efforts at forging links with GPs is briefly mentioned and the CHC offers to give support and assistance in involving patients.

A practical complaints guide

South East Kent CHC has produced an eminently practical pack to help people who may want to make a complaint against the NHS. Separate sections on different coloured paper guide the user in making different kinds of complaints, for example about hospital treatment or about GPs. The sheets give local information on the services which people may be complaining about. Thus one list shows that the Vicarage Lane Clinic in Ashford is part of the South Kent Community Healthcare NHS Trust and it gives a contact name and address. This simple information should save patients a good deal of time and uncertainty. The sheets also suggest how patients might go about making a complaint. Sample letters addressed to the relevant person in the health trusts, are included for people to copy and adapt.

NHS Complaints Advice Service: Self Help Pack
South East Kent CHC