

# ASSOCIATION OF COMMUNITY HEALTH COUNCILS FOR ENGLAND AND WALES

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## GROUP SESSION REPORTS BY RAPPORTEURS

<u>Group Session</u>	<u>Page</u>
Focus Groups	2
Breast Care - The Services We Offer and Discussion of Future Service Development	5
Getting It Right From the Start	7
User Involvement - The Way Forward for the NHS	10
Confidentiality of Health Records and Security of Clinical Information Systems	12
How Does Your Garden Grow? Monitoring Quality in Children's Health Services	14
Standards of Practice for Doctors (Sessions 1 and 2)	17
Giving Strength to Patient Feedback - Taking Forward Consumer Audit Techniques	21
Quality in Dementia Care - A Model	24
Collaboration in a Primary Health Care Led NHS (Sessions 1 and 2)	29
Developing Women-Centred Maternity Services	35
Care in the Community: Rhetoric or Reality	39
Carers are Part of the Team	43
Patient Participation at the Surgery - How NAPP Can Help With This! Setting Up Groups!	50
The Ombudsman's Role in the New Complaints Procedures	52
Citizens' Juries (Sessions 1 and 2)	54
A Guide to the Internet	57
The Privatisation of Long-Term Care	59
Windows 95 and Office 95	62
Developing Primary Care for Black and Minority Ethnic People	64
By Accident or Design - Improving A & E Services	66
As a 'Community' Health Council, Do We Really Involve our Community?	74
Performance Standards Through Chartermark	80
Breastfeeding - Good Practice Guidance to the NHS	85
Representing the Public?	88
GP Fundholding: The Benefits	90
Training for Delegated Health Care Tasks in the Community. Whose Responsibility Is It?	92

2  
FOCUS GROUPS

**Session Leader: Margaret Tozer, Chief Officer, North West Anglia CHC**  
**Rapporteur: Jenny Hunt, Aylesbury Vale CHC**

Focus groups have been used by the CHC in North West Anglia to bring in the perceptions of the wider public into Health Authority planning, known as the Healthy Horizons Programme. The new CHC emerging from the merger of two former CHCs, with different ways of working with a new Authority, noted that one vital link of DHA consultation was missing - the general public - although the voluntary sector, health staff and statutory agencies had been involved. The suggestion was put to the Authority by the CHC that they should undertake this role of public consultation working in tandem with the Authority who would meet CHC costs. Reassurances were needed that this way of working was acceptable to people both in the NHS and those participating in the exercise. The agreement between the Health Authority and the CHC contained a proviso that any issues raised were within the ownership of the CHC.

As with any such piece of work of this nature training was essential. The CHC used an independent trainer for a two day intensive workshop for its members and staff at a cost of £800 per day. The value of anecdotal evidence was from the beginning recognised so long as there was consistency of approach. A code of practice was drawn up by the CHC and consulted upon with the Health Authority and the voluntary sector.

The pattern of work involved the Health Authority and Social Services holding a series of workshops, of about twenty people at each, for purchasers, providers [including the private sector] and also separate workshops for the voluntary sector looking at values of current health services. At the same time the CHC ran Focus Groups for the general public which were much smaller and consisted of between 8-10 people who had been recruited in a variety of ways. Views were collated and brought together in a Consensus Conference so as to form part of the whole and culminating in the production of a consultation document being circulated within the community. Projects run for about three months with the CHC element managed by a Steering Group of 3 CHC members and the Chief Officer. At the end of the project the outcomes are fed back to the local community.

As would be expected, the work was time consuming and labour intensive. Members and staff commitment was essential. Members had to be extremely clear about the objectives of the work and their involvement in this. Identification of the issues from users and carers was important. The need for confidentiality was stressed. Members attending at the Focus Groups

kept index cards by them so that people requiring follow up on personal individual concerns could leave name and address which the officer team followed up. Members acting as facilitators also needed to be sensitive to the needs of those participating and that some may wish to talk on a one to one basis talking through distressing situations. It was mentioned at the conclusion of every event that support could be provided for people requiring same.

No scientific system for establishing Focus Groups was used, although there was an agreed protocol. The voluntary sector, which may have been involved in the Health Authority workshops, was asked to participate in the public work by nominating one of its members or a user of services to the Focus Groups. Advertisements were placed in the local press and a publicity leaflet with tear off strip for return was used at various outlets. The number of sessions on each specific topic varied. For instance on Mental Health services there were five sessions plus two sessions on a one-to-one principle. On Services for Older People there were seven sessions plus three open forums, for Disability thirteen sessions and for Children and Families four, with two on a one-to-one basis. The CHC reimbursed the expenses of those participating.

People who had contacted the CHC offering to take part in the Focus Groups were given the name of a CHC member acting as a moderator for a specific Focus Group and were asked for permission to pass details forward. If the CHC member acting as a moderator was not familiar with the locality a second CHC member familiar with that locality/community was co-opted to act as the "dogsbody", with the CHC office providing any support required. Focus Groups were held at different venues across the District. At the beginning of each session an agreed introduction to ensure consistency was conveyed to those attending. All sessions were taped.

Each tape required 15 hours of a typist's time to process and each Focus Group involved at least one and a half tapes. This work was undertaken by CHC staff with agency staff being used for routine office duties.

The Chief Officer and CHC members of the Joint Panel sifted all transcripts identifying key concepts. These were coded and drawn together to enable a report to be produced highlighting key issues and making recommendations with a commitment from the CHC to take forward any issues. The report was sent to all participants and where it had not been possible, for reasons of confidentiality, to include comments a note sent to the person, offering to take it forward on a personal basis. Key issues from the Focus Groups were then

fed to the Consensus Conference, a CHC officer or member, using the words of people using the service.

At this point the audience challenged the self selection of the groups of people participating in the Focus Groups but Margaret contended that the work was an integral part of CHC work and the core role of the CHC continued.

During the following discussion a challenge was made as to the independence of the CHC in undertaking this process and how it could be perceived by the public. Was it sufficiently removed from the DHA process? Why were the Health Authority not doing it themselves? Were the CHC raising expectations which could not be met? Margaret responded that each project had very clear aims and objectives so that the public was clear about the CHCs role in the process.

Margaret felt there were benefits for the CHC in undertaking this work, including members involvement in using their knowledge, skills and experience. Enhancing their knowledge of the communities they represented and putting into focus both health and health related issues. In addition the CHC had an understanding of the Health Authority's strategic planning which facilitated monitoring of the Health Authority. They were able to do this without being involved in the discussion or decision making process [they had taken the conscious decision not to be part of the Healthy Horizons Programme]. This has also increased credibility of the CHC within its community.

Evaluation was also discussed. Various procedures had been put in place testing back with participants and regular updates on progress of the Strategy from the Health Authority. An offshoot had been a GPFH practice being quite keen to use the CHC in similar work.

Focus Groups are a tool which can be used for a number of pieces of work in assessing quality standards, working with ethnic communities and disadvantaged groups, Patient's Charter Standards etc. It is, however, important for CHCs to retain control - the question of ownership was raised by more than one delegate. Who has ownership was obviously of concern - was the CHC being used as pairs of hands? Any such work needs to be carefully planned, monitored and costed at the outset. Good quality training for members and staff is essential. It is important for CHCs to work with and for their local communities endeavouring to influence the type and quality of health care provided. Margaret Tozer gave a very good presentation illustrating how Focus Groups can be used to do that.



## BREAST CANCER CARE - THE SERVICES WE OFFER AND DISCUSSION OF FUTURE SERVICE DEVELOPMENTS

**Session Leader: Jane Walker, Area Co-Ordinator-North, Breast Cancer  
Care**

**Rapporteur: Beryl Furr, Southend District CHC**

The aim of the workshop was to offer an outline of *Breast Cancer Care*, its history, development and the services it offers to people with breast cancer and other breast related problems. In her introduction Jane said that 90% of breast problems were 'self detected' with only 10% picked up by the screening services. She invited participants - all women - to introduce themselves and say why they had selected this workshop and how they wanted breast care services to develop: their views could help inform a national Working Party currently looking at the development of services. This set the pattern for the meeting and allowed Jane to respond to a wide variety of questions and comments about breast care and cancer services.

Thirteen out of the 24 participants gave personal accounts of their experiences as breast cancer patients. Some painted a pretty dismal picture of medical and nursing care and of a variety of failures in communications. A few were prompted to become CHC members as a result of what happened to them. Some were CHC representatives on local Breast Cancer Implementation Groups while others were from CHCs that faced cuts in local cancer services. It became clear that services varied considerably across the country and we shared a number of examples of good and poor practice in breast care services.

- **Good** included 'one stop' services offering rapid screening, diagnosis and care under one roof - though Jane was cautious about the roller coaster effect of rapid response services - Breast Cancer Care prefer a 'two stop' approach, giving women time to come to terms with the diagnosis before considering treatment options. Others asserted women's right to know as soon as the professionals know - *'It's awful to think they know something about your body that they won't tell you'*. We applauded the development of Macmillan's Good Practice Guidelines - which must be rigorously monitored.
- **Poor** included a shortage of local breast specialists, meaning that women (and the few men who also have breast cancer) may be seen by general surgeons or be referred as extra contractual referrals to other districts. There were failures to diagnose and poor follow up care. Younger women with family histories of breast cancer were being denied mammography, older women were 'dropped off' the call and recall programme. Prostheses services limited, rather than promoted choice. There was a need to extend the 'Forrest' Screening Programme to include all women from 40 to 69 and better publicity to inform women outside the current age bands about their right to mammography.

### WHAT ARE GOOD BREAST CARE SERVICES?

The unanimous definition was that we need local, high quality comprehensive services for breast cancer. It's not a rarified disease - keeping quiet about it won't make it go away! There are 32 different breast conditions. Good services provide:

- **Quality and Access** - Prompt referral to high quality, comprehensive local services
- **Speed** - A firm diagnosis within four weeks of referral

- Appropriateness and Choice - Good quality, timely information which enabled them to make appropriate choices of treatment, methods of care and aftercare, and enabled women to select suitable prostheses and other aids
- Support - Health professionals to recognise the traumas experienced by cancer patients and their families and to offer more counselling and support.

### 'BREAST CANCER CARE'

Established in 1978 by Betty Westgate, MBE, and based at Kiln House, 210 New Kings Road, London SW6 4MZ. The organisation, which has 25 members of staff and 400 fully trained volunteer workers throughout England and Wales is part funded by the NHS. It provides free help, information and support for women with breast cancer or other breast related problems. It aims to be non directive or judgmental, to respect women's choices and to 'know where the woman is standing' NOT to claim to share her experiences, which are unique to the individual. They advise *'Don't just accept what's being said: press for written unprejudiced information on which to base your decisions'*.

Breast Cancer Care produces a range of booklets and information leaflets, mainly free to patients and supporters, and at low cost to others. They provide a Helpline, a free and impartial Prosthesis Fitting Service and have eighteen Partner Volunteer Support Schemes. They maintain a database to ensure a good 'match' between clients and supporters.

### WHAT CAN CHCS DO?

Breast Cancer Care and CHCs share a common problem - the public tend to find out about us by accident! But organisations can work together to promote mutual visibility. CHCs can:

- Press for national standards in breast cancer services - The Macmillan Foundation produce a list of ten minimum standards - and negotiate with health authorities and GP Fundholders for these to be included in quality specifications
- Support individual users and feed their concerns into the system. Help them to use the range of practical and support services provided by Breast Cancer Care and other agencies - for instance few patients realise that if they change weight they have a right to a new prosthesis - the Prosthetic Fitting Service makes sure that its users are fully aware of all the issues as well as giving impartial, independent advice on the best prosthesis for the individual concerned.
- Campaign to raise public awareness of breast issues - debate the Calman Report in public, focusing on access, appropriateness and quality of care
- Act as an 'honest broker' providing information to users and monitoring standards.
- Enter the CHC on Breast Cancer Care's database to receive regular newsletters

### Further reading - suggestions from the workshop included:

*Grimsby CHC - Breast Awareness Campaign - Sept-October, 1995.*

*Harrogate CHC - Breast Cancer Services - a user perspective - July, 1995*

*Palliative Care Service Use by Black and Ethnic Minority Groups in Leicester - in partnership with 'Coping with Cancer', 1994. Details from Leicestershire Health.*

*Macmillan Foundation - Self Help leaflet with Ten Minimum Standards for services, 1995 - Breast Cancer Campaign, Room B, Anchor House, 15-19 Britten Street, London SW3 3TZ.*

*Breast Cancer Care - leaflets and publications. Their newsletter regularly suggests further reading. Address above. National Freeline 0500 245 345.*

## GETTING IT RIGHT FROM THE START

**Session Leader: Anne Leonard, Research Officer, SCOPE**

**Rapporteur: Angeline True, Preston CHC**

**Anne Leonard**, SCOPE welcomed participants to the workshop and explained that in June 1994 SCOPE had published a document which outlined parents views and experiences of the way they were informed that their child had a disability. Subsequently a working group had been established bringing together both voluntary organisations, parents and professional organisations to consolidate and extend good practice.

A video entitled "Right from the Start Strategy" was then shown. (This is available from SCOPE). The video covered:

- ▶ So what is the Problem?.
- ▶ Findings of the SCOPE study.
- ▶ Research carried out.
- ▶ The legal background.
- ▶ Recommendations for improvement.
- ▶ Action required.

**Carol Stacey**, mum and paediatric nurse then explained her experiences of being told her child had a 'disability':

Carol had wanted to have a home birth and as such was recommended to have a late scan to check everything was alright. The scan discovered a 'problem' and she was placed in a side room awaiting the doctor. At this time she was not too concerned as she thought this was simply a ploy to encourage her to have a hospital birth. However the doctor (who she had never seen before and never saw again) explained that the scan had shown water on the brain (hydrocephalus) and that this would need to be sorted out, he then left. Carol and her husband then had to travel 7 miles to a Manchester hospital by car to have another scan to confirm this diagnosis, (neither of them can recall this trip). At this scan they were informed that she was having a baby boy and that the diagnosis was correct. They then had to travel back to the Oldham hospital, again by car, with the results, to inform the staff.

Carol was aware that her mother had also given birth to a baby boy with hydrocephalus, who had died, and that this was obviously a genetic condition. She felt very apprehensive about telling the family the news. She described this as feeling like she was in 'a black hole with no bottom'.

The day after Thomas was born she saw the Neurosurgeon who was wonderful. She sat with them for at least an hour and discussed Thomas's condition. She was compassionate and did not fill them with high hopes but was very truthful. When she did not know the answers to their questions she simply said so.

Looking back, as a nurse, Carol felt the way she had been informed was average and that there were so many things that could have been done to make things easier for her and her husband. For example, the maternity unit was the wrong setting, for example, following the scan she did not have access to a private phone. No one had planned how they were going to inform them. The professionals had to understand that they did not know how people felt when faced with such a situation, and if parents are not informed well then barriers are built on feelings of mistrust and resentment.

Professionals needed to be reminded that every situation was different but there were basis rules which needed to be adhered ie: standards to be applied.

Anne Leonard said that the Carols experience echoed those experienced by people who were shown on the video and for this reason the 'Right from the Start' initiative had been introduced. The working group had drawn up a template asking people to think about good practice. They had decided that the reason the service had not improved was simply that people had not thought through issues and attitudes which had lead to bad practice. Too often the disability rather than the baby became the whole issue. The purpose of the template was to value the child and the parents. This was available to all Health Authorities and Trusts.

Claire Lees, Area Co-ordinator, Birmingham and Solihull explained her role in working with SCOPE. She not only worked with individuals on an one to one basis and in group work but also supported national campaigns. She explained that she had previously worked with people who were terminally ill with cancer. To her the difference between cancer and cerebral palsy was that death from cancer was a tragedy, yet cerebral palsy was only a tragedy because society saw it as one. Hence, society undervalued the child's worth.

Claire had noted that standards in diagnosis and disclosure of cerebral palsy were not common place and as such had established the West Midlands Disability Consortium which aimed to gather good practice information, promote the use of the template and develop strategies for good practice. Local awareness of the project had been raised by giving talks and presentations. However, further work was needed to develop this work beyond the Birmingham area.

Claire had also assisted in the disability equality training provided by parents of children with disabilities and people with disabilities themselves. One recent success was that whereby a Consultant had asked for and arranged a training session with staff at the local hospital. SCOPE had now employed a trainer to further develop this work.

Nadia Dawson then went on to explain the way both she and her husband had been informed of their daughter's disability. Five weeks prior to the delivery date Nadia gave birth to Alice who had to be ventilated as she was not breathing. They were told that her condition was not stable and that the staff had concerns; the Consultant said the baby was "far from well". Later brain injury was confirmed by a CT Scan.

Both Nadia and her husband and their other daughter Lucy were trained to do specialist procedures. The Consultant was approachable, made time to answer their questions and gave honest answers. On some occasions he reserved judgement when he simply did not know the answers. Both Nadia and her husband felt that if the Consultant knew something, they knew it too.

Support was received from the paediatric nurses, health visitors and social workers and the audio/visual aids department. Individual needs were not overlooked and emphasis was placed on them being a normal family unit. They dealt with issues as they arose and professional support was

available when needed. Lucy enjoyed a loving relationship with Alice who died last year aged 20 months. This reflected the quality of care and support they had received "Right from the Start".

A question and answer/discussion session then followed:

Q: How can SCOPE target the NHSME?

A: Nott CHC - The NHSME does not have much it can influence at a local level any more. SCOPE should target HAs (purchasing plans and quality specifications) but in addition there needs to be a change of culture amongst hospital staff. Suggest that a two pronged approach targeting all purchasers and training institutions.

Bury CHC - The College of Nursing do try to teach how to delivery bad news to patient. Suggest you contact the Schools of Nursing.

Croydon CHC - Local CHCs have a responsibility to shame their local HAs into doing something. However, local SCOPE branches need to contact CHCs.

Dewsbury CHC - It is unacceptable that parents should be told such information in this appalling manner. CHC s can be a useful alliance. The issue of disability awareness needs tackling and society's values - we need to change people's attitudes. This is extremely difficult as we all seem to be fighting for our own. Social Services could play an important role.

(Anne - This is the reason the model adopted by SCOPE challenges attitudes by involving people with disabilities as trainers).

Bromley CHC - CHCs could help challenge attitudes by ensuring that they had someone with a disability on the CHC. The aims of SCOPE should be broadened to tackle the way adults are informed of their own disability. This is just as bad.

(Anne - SCOPE agrees but has to focus its actions. SCOPE is aiming to teach good practice in communication skills which should hopefully benefit all).

Q: How are you validating progress and how are highlighting good practice?

A: Anne - SCOPE are keeping a catalogue of good practice and a CD Rom has been developed showing good practice throughout the country in the form of an interactive map of progress being made.

SCOPE are crudely monitoring impact through the training and use of the template. However, they would have to evaluate how effective the project has been, probably by auditing what people said happened to them. In a few years time they would be looking for money to do this.

Q: It is important to tackle general attitudes however where do family and friends fit into the situation, especially 'Grandma'? From personal family experience it is not just parents who need professional support and medical information.

A: Carol - The hardest thing for me to do was tell my parents. Some hospitals have developed family support groups where any member of the family could attend.

Q: To Carol; as a nurse do you feel you have changed any attitudes within your hospital?

A: Yes, but often I find it hard to put together the professional role with the parent role when I feel that I was short changed. Eg: I tackled a physiotherapist who I felt had handled a situation very badly. She was very upset but understood when I explained things to her. I have considered whether or not I should give up nursing but at the moment feel I should stay and fight from the inside.

## USER INVOLVEMENT - THE WAY FORWARD FOR THE NHS

**Session Leaders: Angela Schram and Tony Russell, Breakthrough**

**Rapporteur: Howard Lawes, Bristol & District CHC**

Breakthrough is a national bi-monthly magazine produced entirely by sufferers/survivors of mental illness/emotional distress, and by carers. Its' principle aims are to educate, inform and, most importantly, to open up lines of communication between service users and the professional caring services.

Formed six years ago (and initially called Patient Power), Breakthrough works with NHS Trusts and Purchasers, and occasionally with Social Services Departments to promote partnerships between service users and service providers. Additionally, because the user movement is fragmented, Breakthrough works to open up lines of communication. They see CHCs as major allies in this process particularly because of their statutory role and their excellent local links and networks.

Recently Breakthrough, through their magazine, challenged providers to ask themselves the following questions of the way they deliver their mental health services.

- do you consult with users of your services?
- does your Board meet with users?
- is your Chief Executive accessible to users?
- do users have a say in planning and provision of services?
- how many user groups do you consult with?
- do you have a user representative as a Non-Executive?
- do you provide information leaflets for users?
- do you have a Patients Council?
- do you have an Advocacy Scheme?

Providers were also asked about the range of services and therapies on offer and the support provided to users and user groups. Although not a formal survey providers were asked to consider how they performed in these areas.

In the discussion following the presentation participants were asked to identify issues and concerns relating to mental health services and empowering users. The following are just some of the points raised.

1. When acute units and long stay hospitals are closed it is important that community services provided in their place meet the needs of users. Tony Russell pointed out that the shape of community provision/new provision is not influenced by user involvement. CHCs can be pro-active in promoting this and enabling the provision of a quality service.
2. When acute units are closed and the service re-provided, users can lose out on travel benefits currently payable for travelling to hospital. This needs to be highlighted and addressed.
3. Too often national policy on mental health services is formulated in response to media scare stories concerning "dangerous" patients. This can lead to a service not provided in the interests of users.
4. Users need a service that is accessible, but this is difficult because of the way responsibilities fall to different agencies. The artificial social/medical divide results in a fragmental service with users losing out.
5. User involvement needs to be resourced to enable people to take part. This led to a discussion on how representative user groups could be (and how representative CHCs are), and the need to ensure everyone had a voice. The role of advocacy was underlined, however it was also agreed that individual advocacy was insufficient and there should be recognition of the role of advocacy in campaigning for better services.
6. Arising from the discussion about resourcing involvement came a comment that Health Authorities resist investing in the communities they are supposed to be answerable to. This means that the communities can not organise effectively and have to deal with the Health Authority's Agenda instead of setting their own.
7. In looking at influencing service providers it was noted that the vast majority of provision is through GPs but this is the hardest group of professionals to work with.
8. Throughout the country there is evidence of good practice. It is important that there is communication across the NHS to stimulate debate and action on good practice. At present there is insufficient communication.

All through this stimulating and challenging group session Tony Russell emphasised the crucial role of CHCs in bringing people together, providing information, opening up channels of communication, working with users and user groups, bringing pressure for change, and acting as honest broker. Tony also urged CHCs to subscribe to Breakthrough.

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**CONFIDENTIALITY OF HEALTH RECORDS AND SECURITY**  
**OF CLINICAL INFORMATION SYSTEMS**

**Session Leader: Dr Fleur Fisher, Head of Ethics, Science & Information,  
BMA**

**Rapporteur: John Godward, Airedale CHC**

This Seminar was very well attended, and so it should have been, because the subject should be of major concern to all organisations which represent patients in the NHS.

The subject was excellently presented by Dr. Fleur Fisher of the BMA, whose understanding of the complexity of the subject did not hide her strong commitment to the need for urgent reform of the law and regulations covering patient clinical confidentiality.

The Hippocratic Oath incorporated the principle of medical confidentiality into the doctors' professional ethics.

The new organisation of the Health Service into Health Authorities and Trusts, however, has led to the destruction of clinical confidentiality. The information from the Trust is passed on to the Health Authority, with the name, address and postcode of the patient, as well as the diagnosis and treatment. The full identification of the patient is revealed and can be accessed by anyone using the data for planning purposes.

Without the patient's informed consent, the information is used for treatment, billing, epidemiology, planning, audit and research.

The Government's view is that the patient has consented to the use of this confidential information by 'the patient being there'.

A huge difference in opinion and attitude has developed between the BMA and the Government, to the point where the BMA has published a draft Bill to try to improve the patients' lot.

The BMA's view is that the patient should give informed consent as to who may see their personal data.



Information Technology means that information can be amassed quickly to aid efficiency economically, but it also means that confidential information can be passed quickly to those who need to access it, without the patient knowing that this is happening. Yet Information Technology is capable of ensuring that records which are confidential, are scrambled, encoded or crypted.

The destruction of confidentiality continues with the development of the NHS-wide network, centralised database.

The BMA is campaigning for an NHS Data Security Policy for clinical information.

Without such a policy and without it being made a criminal offence to reveal clinical, confidential information, patients' belief that anything said to a doctor is protected by his oath and ethics, is simply a myth.

Some hospitals' systems contain personal health information on a million patients, with all users having access.

Moreover, Trusts with financial problems may be tempted to sell information which they do not regard as confidential, to commercial outfits.

Privatisation of Information Technology and processing of records by commercial organisations, further weakens and exposes clinical confidentiality.

All this points to the need for -

An adequate Data Security Policy  
Competent technology  
A culture shift required within the NHS.

Community Health Councils have a role to play in demanding that patients are made aware of the uses to which confidential, clinical information may be put and in securing adequate policies and laws which will protect patients from abuse and exploitation.

**JOHN D. GODWARD**  
Chief Officer of Airedale CHC.  
12th July 1996

**HOW DOES YOUR GARDEN GROW?**  
**MONITORING QUALITY IN CHILDREN'S HEALTH SERVICES**

**Session Leaders: Anne Rivett and Peg Belson**

**Action for Sick Children**

**Rapporteur: Glenys Syddall, North West Regional Association**

Peg Belson outlined the principles for child health care:

*Rights of the child* - the right to have information appropriate to their age and maturity; to express their views; to have absolute privacy and confidentiality; to have the highest attainable standards of care.

*Child and family centred service* - there are many hospital areas where parents are not allowed to accompany their child (x-ray, emergency rooms, treatment rooms), and not all hospitals have provision for parents to stay overnight; there needs to be a child friendly, safe welcoming environment, with staff trained to communicate and with facilities for disabled children.

*Partnership with parents and children*

*Listening to children, young people and parents*

*Integrated and comprehensive service*

These principles underpin Action for Sick Children's document "Health Services for Children and Young People" published in February 1996.

The best interests of the child should be paramount, and many health authorities are trying hard to focus services to ensure they are in the child's best interest.

The cultural needs of children from minority populations must be met. Peg referred to Action for Sick Children's training pack on multi-cultural care "Caring for all our Children".

Anne Rivett then outlined recent developments:

*Children's service plans:*

New Departments of Health, Education & Employment and Social Security guidance (LA/96/10) requires children's services plans for all children to be drawn up from April 1996 for introduction in April 1997. This results from Audit

Commission research in 1994 "Children in Need". Social services departments are to take the lead and must consult with health authorities, trusts, police, schools, etc.

*Mental health:*

The NHS Executive sees mental health as one of its six priorities, but adult mental health is concentrated upon. Only 64% of health authorities have a strategy for children's mental health services. Many children's mental health services are poorly managed or non-existent, and children are often placed in adult psychiatric wards. Treatment is often aimed at trying to stop bad behaviour rather than looking at the reasons for the child's distress. Discontinuity of care can be a problem when children reach the ages of 14 or 16.

*Quality v access:*

There is a gradual move towards centralisation and the closure of small units, which can obviously cause problems for parents visiting. The British Paediatric Association recommends that children's units be based on the same site as maternity units with at least 3,000 births a year.

One CHC felt that its residents would argue for local accessible services without realising that this may not offer the best quality. CHCs need to raise the issue of quality in public debates about service changes.

*Primary care led services:*

How much do GPs know about children's needs? Do fundholders refer children to wards with no paediatric nurses, or to adult wards? Not all private hospitals to which children may be referred have paediatric surgeons, nurses or anaesthetists.

*Carer's Act .*

*Children's Patients' Charter:*

The Charter aims to raise standards, but can trusts meet the targets? The wording allows trusts to opt out, ie it says "should" "ideally" etc, rather than "must".

Action for Sick Children feels it is too long, too complex, and difficult to understand in places. Its audience is unclear - is it aimed at children or parents? [Many CHCs wholeheartedly shared this view; another queried how children were meant to know about the Charter when its health authority had been supplied with only 600 copies, yet it serves 35,000 young people].

## **Monitoring the Children's Charter**

At this stage, two groups were formed, each looking at one section from the Children's Charter. One group concentrated on what the Charter says about children in hospital, and one group looked at caring for sick children at home.

The groups considered what the most important issues were for young children, older children and young people, and parents and carers. They discussed how services could be audited, and how CHCs could help strengthen the voice of children and young people in local health services. Ideas on this included:

- Lobby of health authorities and trusts

- Press releases, interviews on local radio

- Children's forum

- Stakeholders' conference

- Surveys on children's wards and clinics and in schools

- Children's network via the voluntary sector

- Contact through Homestart.

STANDARDS OF PRACTICE FOR DOCTORS

**Session Leader: Alan Kershaw, Asst Registrar and Jo Mullin,  
Administrative Officer,  
Standards & Education Division, GMC  
Rapporteur: Heather Wood, Huntingdon CHC**

The seminar was to bring to CHCs' attention, the role of the General Medical Council (GMC) and to highlight their new guidance for doctors on standards of practice and ethics. All attendees were given a copy of the key document "Good Medical Practice" (which all CHCs should have received).

Alan Kershaw, Assistant Registrar and Head of Standards and Education Division, explained the role of the GMC, principally to protect Patients and to guide Doctors. The Council is not made up solely of doctors but currently has 13 lay members out of 102 members. By November 1996 they will have 25. They are funded solely by doctors' registration fees and are not an NHS or government body, neither are they a Professional Association (like the BMA), or responsible for training (like the Royal Colleges). The new guidance is part of their changing image and they would welcome invitations to speak to CHCs. They have been most known for 'striking off doctors' but in fact that affects only about 25 per annum out of 150,000 registrations (0.016%). With regard to reinstating a doctor, up till now they have only been able to say "No" or "Yes". They would like to say "Yes but....." and asked CHCs to consider pushing for such a possibility. Then they could insist on retraining, counselling etc, as appropriate.

The Council was set up by the 1858 Medical Act so that we, the public, can be protected. The GMC set standards for doctors and oversee their education. Their register is always up to date - although locally held Medical Directories are, inevitably, not so and are not produced or checked by the GMC. One can always check a doctor's registration by telephoning the GMC. Their previous publication, "Fitness to Practice", the 'Blue Book', emphasised the negative (generally under the 5As of Advertising, Adultery, Addiction, Association and Abortion!). It was only available to medical practitioners. However, the new publication, "Good Medical Practice", is much more positive in attitude and is being widely distributed. A particular feature is the list of fourteen principles that doctors must adhere to - six of which apply to their relationships with, and care of their patients. The others reflect professional skills and keeping up to date as well as working with colleagues "in the ways that best serve the patients' interests". This is good news for CHCs. We are likely to see these fourteen principles on many publications in the future - in particular, all new medical students will get them as a bookmark.

Jo Mullin, the Administrative Officer, Standards and Education Division, spoke further about the GMC's great push to revise completely the education of Doctors, particularly in skills and attitudes and how to keep up to date throughout their working lives. The GMC did a lot of study in other countries on how they taught Communication Skills. A big criticism of the previous course was that it was years before a student saw a patient. Some are now 'allocated' to a real patient e.g. a family with a baby, elderly person, someone with disabilities, and they accompany them for several years - seeing it all from the patient's viewpoint. There is also more discussion of ethical issues and of their own feelings. A book was distributed entitled "Tomorrow's Doctors" on undergraduate medical education.

There was a lively question time, particularly on the 'striking off' of 'difficult patients' especially the elderly and any with long term mental illness, but a general welcome for the fourteen principles. There was also discussion of medical standards of doctors trained in other countries and the possibility of having a World Medical Organisation where countries would be admitted when up to standard (thought to be a 'good idea').

CHCs should be receiving the GMC Annual Report soon. We were asked to think about how to help them to implement the fourteen principles. As mentioned above, they would be pleased to speak at CHC meetings anyway (and were commended by those with experience of these talks).

Heather Wood, Chief Officer, Huntingdon CHC.  
29.07.96

## The duties of a doctor registered with the General Medical Council

Patients must be able to trust doctors with their lives and wellbeing. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- make the care of your patient your first concern;
- treat every patient politely and considerately;
- respect patients' dignity and privacy;
- listen to patients and respect their views;
- give patients information in a way they can understand;
- respect the rights of patients to be fully involved in decisions about their care;
- keep your professional knowledge and skills up to date;
- recognise the limits of your professional competence;
- be honest and trustworthy;
- respect and protect confidential information;
- make sure that your personal beliefs do not prejudice your patients' care;
- act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;
- avoid abusing your position as a doctor; and
- work with colleagues in the ways that best serve patients' interests.

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them. For further information on how to apply these principles, please read our booklet 'Good medical practice'.

STANDARDS OF PRACTICE FOR DOCTORS

**Session Leaders: Alan Kershaw, Assistant Registrar and  
Jo Mullin, Administrative Officer,  
Standards & Education Division, GMC  
Chair and Rapporteur: Joyce Struthers, ACHCEW Vice Chair**

THE GMC

Alan Kershaw described the characteristics and function of the GMC as follows: \_

*It is not:-*

a Government body. Doctors pay for it  
limited to the NHS.  
a training body.  
trade union or professional body.

*It is:-*

an organisation of lay people which exists to protect the public and guide doctors

It sets standards in education, conduct, ethics and performance.

**HISTORY:** It was set up in 1858 to create a register of properly qualified doctors. A threshold was established for getting on to the register and reasons for coming off. There was no guidance. Doctors absorbed ethics by osmosis. In 1914 the five 'A's which could lead to a doctor's being struck off the register were made explicit:- Adultery, Advertising, Addiction, Abortion and Association (with unqualified assistants. In 1918 The Blue Book 'Fitness to Practise' came out. Its first page detailed how to get struck off!

Since then development has tended more towards accentuating the positive, culminating in the issue of the package 'Duties of a doctor', comprising four booklets:-

Advertising

Confidentiality

Good medical practice

HIV and AIDS: the ethical considerations

and 14 principles governing good medical practice.

These have been widely distributed to practising doctors, medical schools, private employers and CHCs.

GOOD MEDICAL PRACTICE THROUGH THE GMC (Jo Mullin)

**GMC recommendations for medical schools' curriculum** (The publication "Tomorrow's Doctors" represents a radical departure.)

Undergraduate training must give doctors the skills to equip them to keep up to date and develop for the rest of their working lives i.e.:

clinical skills

training as to attitude and behaviour,

communication skills

*Survey of what is happening in medical schools now*

Practical training in a safe environment e.g. for dealing with bereavement, the consultation. Actors are sometimes used for role play. Videos are also used.

Discussion of experiences with colleagues

Long-term programme for GPs

Students are allotted to families so that they can see health care from the patients' point of view

Discussion of ethical and attitudinal issues

Relationships with e.g. judges, lawyers, social workers

Participation in outpatients' clinics

Students are given copies of 'Duties of a doctor'.

*Improvement of the educational content of the pre-registration year*

The GMC view is that this should be regarded as the 6th year of medical education, a consolidation year. At present it consists of too much routine without educational content.

**MAIN AREAS OF QUESTIONING**

How to change attitudes of existing practitioners

The role of the CHC. It was noted that the GMC has same problem as CHC in convincing GPs that they are not a threat!

Registration standards for foreign doctors

Continuing education, need for limited registration and re-registration. It was noted that from 1 January 1997 Specialist Registration i.e. 'specialised for work being undertaken' will be a requirement in law.

Clinical effectiveness

How to spread good practice. It was noted that the new Independent Review Panels would be auditing good practice and spreading messages. The IPRs could feed into the GMC.

Shortage of doctors

Joyce Struthers

14 July 1996



## GIVING STRENGTH TO PATIENT FEEDBACK - TAKING FORWARD CONSUMER AUDIT TECHNIQUES

**Session Leader: Richard Wiles, Head of Research,  
and Veronica Santorum, Training Officer, College of Health  
Rapporteur: Roselyn Wilkinson, ACHCEW**

Veronica started the session with a brief introduction to the College of Health, whose mission statement is 'keeping the NHS focused on people'.

Richard then spoke about the importance of good research design. The main questions to ask are:

- What are you trying to find out, and why?
- What is already known (demographic data/data on service use/ literature review)?
- What will it cost?
- How long will it take?
- Is the approach ethical? (The general rule of thumb is that you should seek ethics committee approval whenever the research involves NHS patients).

It is much more useful to do what you can within the required timescale than to leave unfinished a more ambitious project.

There are a range of research methods to choose from: quantitative/qualitative, focus groups, telephone surveys, mystery shopper (see recent ACHCEW Briefing on research for more detail).

Sampling is often raised as an issue of concern. In fact, qualitative research is not about being statistically representative. If you do wish to sample appropriately, consider who you want to involve - for instance, people who aren't using a service. There are various sampling methods - random, systematic, quota, purposive, snowball. It is more important to get a representative sample of the sub-groups you're interested in, such as ethnic groups or non-users.

Each method is relevant for finding out different things:

Observation works well for CHCs and can be useful when staff act as observers of the service they provide.

Interviews will get very different results depending on whether the questions are structured or semi-structured.

Focus Groups need trained facilitators/observers. They are useful to help identify issues of most concern and to help define user sensitive questionnaires or to measure user reaction to proposed service delivery changes. Focus groups can be used for rationing decisions. If the health authority is proposing this, bear in mind that the health authority is still accountable for the decisions they make.

## Giving Strength to Patient Feedback - continued

The Group then split up into workshops to look at three different case studies. In each case, two groups considered how to approach the question.

### CASE 1

Selcham health authority is responsible for health care in a multi-ethnic and socially and economically deprived area of Inner London. There is a high rate of termination of pregnancy within the district (including both terminations performed within the NHS and privately). At the health authority's instigation, the Community Health Services Trust has introduced several new family planning clinics aimed particularly at young people. These were launched with a major publicity campaign, but during the first year take-up has been disappointing, and so far there has been no effect on the termination of pregnancy rate.

Thewby health authority has asked Selcham CHC to investigate. How can it do this?

Group 1 posed the question 'Why is take-up so poor?'. They decided to look at access, including the information available about the service and the incidence of female GPs. They wanted to find what family planning advice GPs were giving and the availability of emergency contraception. The issue of confidentiality was thought to be important, and what information was available post termination. They decided to speak to sixth-formers to find out why they didn't use the service.

Group 2 also considered how to get into contact with non-users. They felt focus groups might help to find out what the barriers were. To reach the right people they considered going to youth clubs, using youth outreach workers and using the snowball technique (asking one person to refer them on to another - this technique can work well with sensitive issues). They also considered observation in the clinics to see what is going on there.

### CASE 2

Marston Health Authority is responsible for health care in a multi-ethnic and socially and economically deprived area of Bradford. The local Mental Health Trust, with support from the health authority, has established an intensive home support team for elderly people with dementia, and two day centres, and has stopped admitting confused elderly people to the local psychiatric hospital (which is now scheduled for closure).

Marston CHC fears that the change has been motivated more by a desire to accelerate the hospital closure than by a commitment to improve the quality of life for elderly people. It has also received a couple of complaints from carers, who have tried unsuccessfully to get the people they care for admitted into hospital, and feel they cannot cope any longer. The health authority still supports the overall strategy, but is concerned that the decision to halt psychogeriatric admissions may have been premature.

How can the CHC investigate?

Group 3 felt the main question to answer was 'What is the quality of life for elderly people and does the new strategy match up to this?'. They decided to involve focus groups of

## **Giving Strength to Patient Feedback - continued**

carers and elderly people to decide on the components of a quality service and to generate a questionnaire which would help to gather views and to monitor what is happening to other elderly.

Group 4 first wondered whether they had been consulted on this service change - and if not, they would complain. They decided to use both unstructured interviews and focus groups to find out user views on the service from people in day centres and home support service users, and to investigate what the health authority had done to evaluate the service. The group felt it was important to do a 6 month follow up to see if the service had improved.

### **CASE 3**

Lanham Health Authority covers two towns: Lanham, with a population of 230,000 and Fisley, population 120,000. They are 5 miles from each other, predominantly working class with a high level of unemployment. Each town has a general hospital with A&E, but both are run down. There have been difficulties with night-time staffing of the accident and emergency department at Fisley General, with the result that it has been closed on several occasions recently.

Lanham Health Authority has issued a proposal for changing arrangements for accident and emergency services. This consists of upgrading the department at Lanham General Hospital, and closing the department at Fisley General Hospital. At Fisley, the department would be replaced with a minor injuries clinic, in which medical cover would be provided by GPs. At night, this centre would double as a base for a GP night care co-operative, so it would be offering 24 hours cover. The authority is also planning to upgrade five local health centres (two in Fisley and three in Lanham) so that they would have better facilities to deal with minor injuries, and to offer some minor surgery. The health authority has also said that it will be making improvements in out of hours access to GPs.

The CHC is in contact with a campaign against the closure of the Fisley Accident and Emergency department, which has strong support in Fisley. However, some CHC members are attracted by the Health Authority's plan, which they see as a way of improving what is at present an unsatisfactory service. How can the CHC ascertain whether the plan is likely to meet the needs and concerns of local people?

Group 5 took the role of a proactive CHC! They suggested observation in both hospitals, structured interviews with attendees at A&E and locality based focus groups,. They also said they would look at the health authority evidence and examine what services GPs would or could provide.

Group 6 decided to examine hospital information about service demand and to set up focus groups to set up a structured questionnaire. They would hold a public meeting and access the information held by the action group.

## QUALITY IN DEMENTIA CARE - A MODEL

**Session Leader: Jane John, Director - Care Consortium,  
Alzheimer's Disease Society**

**Rapporteur: Margaret Tozer, North West Anglia CHC**

Jane John, the Director of the Care Consortium, a National Department within the Alzheimer's Disease Society, attended the Workshop to talk about quality in dementia care and standards developed for use by the Alzheimer's Disease Society. Jane emphasized that this was one model developed by the Society, but was not the only way of doing things.

### SOMETHING ABOUT THE ALZHEIMER'S DISEASE SOCIETY

1. The Society supports people with dementia and carers through a network of branches, which may also run Day Centres or sitting services, supporting groups and carers. Local organisers all have experience, either of looking after someone with Dementia or of working with the problem.
2. Information and advice is available through the National Office of the Alzheimer's Disease Society and through local groups.
3. Regional Offices - 12 across the country.

The Society has 250 branches and support groups, and run 90 care services (60 day, 30 home). The care is mainly funded through Social Services, but some are Health-based under contract from Health Trusts. Day care ranges from one day a week (Social Club) right through to seven days a week. Similarly, care can be provided from a few hours to a full 7 day a week service.

### WHY IS THE ALZHEIMER'S DISEASE SOCIETY INTERESTED IN QUALITY?

- Needed to consider the whole issue of managing the liability of being in the contract culture. What one branch is doing could affect another if we got it wrong. As a Society, we needed to ensure we were not taking on liabilities we could not meet.
- Said for a long time we don't do care services and although not a policy decision, discovered the Society had some 40 care services. Branches had seen a need to offer support to make a difference to people and their carers. Done without a great deal of support from the Centre and we needed to react to that.
- The overriding reason was around the whole issue of quality. We campaign a lot for improved quality for people; if we are unable to demonstrate quality ourselves, we are likely to shoot ourselves in the foot at some stage.

Having agreed that we needed to describe quality, we established a pilot group (comprising 7 different branches running different services) to start the process of developing our model of quality in dementia care.

## PROCESS

We began by asking people within the pilot group what made them feel valued, and conversely, what made them feel not valued. This led to the agreement of three principles:

- "
  - Individualized care. Every person has an individual personality, a history, likes and dislikes, skills and abilities, and a huge variety of experience. Care services for people with Dementia must be provided in a way that individually recognises and builds on the person's strengths and abilities and maintains their independence; we should not think of people with Dementia just in terms of what powers they have lost.
  - Dignity and respect. Those whose mental powers are failing need, in every way, to be treated as a person just as we ourselves would like to be treated. Care services for people with Dementia must be provided in a way which preserves dignity, treats people with respect, offers choice and safeguards privacy.
  - Understanding and supporting carers. A reliable quality service for a person with Dementia can provide support and respite from the stressful role of caring for someone with Dementia. Care services must have a strong emphasis on carers, using their expertise and experience to improve the care that is offered. "

Copyright Alzheimer's Disease Society 1996.

From these principles has been developed a mission statement and quality policy. Branches manage services within the quality framework of the policy, with support from the Centre, services are not managed from the Centre. Essential that the policy is used to maximize the benefits for the person with Dementia and the carer. The Society will not sign contracts that do not contain what is important in terms of quality. This has been a hard thing to do, leading to the possibility of not developing a particular service, in order to maintain the principles.

## QUALITY POLICY FOR DEMENTIA CARE

When discussing within the Pilot Group the defined elements of a quality service, it was agreed this would include:

- Well-supported staff
- Individual care
- Adequate funding

This enabled the identification of three broad themes:

- Client care - what we actually provide and how we do it.
- Staff - support, training and development.
- Service management and administration - effective and efficient management and administration of services.

From this was developed a comprehensive list of standards, worked out in consultation with the Pilot Group, over a period of 14 months. Looked at all of these as building blocks to try and define quality under each heading. The outcome from each standard must be client-focused, not just a checklist.

An example of a standard that relates to personal care is attached as Appendix I.

#### IMPLEMENTATION

- Currently working on a Care Services Manual to assist people work through standards and to help them in achieving standards within a National framework.
- Obtained funding to take all the Branches through the process. This will allow local discussion, and enable people to contribute and take quality beyond what we have included within the framework.
- Developing a Care Consortium Newsletter to make Care Managers feel part of something very exciting. Central training programme to give people the skills and knowledge.
- Implementation process planned over a 3-year programme to gain commitment, the key principle being that each branch will be working towards achieving standards with an agreed action plan. Wishing to create ownership of ideas, not to foist them onto the Branches.

#### MONITORING

Once Branches have an understanding of the principles of the policy, we will be monitoring improvement over time against the agreed standards. Ultimately, we would wish to be able to demonstrate evidence of improved quality of life as a

result of meeting standards, but I accept that this will be extremely difficult to achieve.

National monitoring will be undertaken by the Care Consortium Audit Team undertaking some sample audits, dovetailing into the purchaser monitoring arrangements.

### CHALLENGES

- Striking a balance between bureaucracy and ownership.
- Purchasers want quality but don't want to pay for it.
- Diversity of services operating within the Society present an enormous challenge if we are to work within one national framework.
- External pressure - people asking for our standards, but currently only an internal document. Don't want other organisations to introduce them without careful consideration.
- Monitoring outcomes - need to be doing cross-agency work to look at this issue.

### WHAT DO WE HOPE TO ACHIEVE?

- Better quality of services leading to better quality of life.
- Influencing others to provide high standards of service.
- Links into our campaigning.
- Ownership of quality in all areas of work - carer support; information services.
- Enhanced profile to our purchasers give us an edge.
- Future opportunities to broaden standards.
- Involvement of carers and people with Dementia at all levels. Our national Audit Team will comprise at least 50% carers as will our monitoring teams.

## 1.10

## PERSONAL CARE

*The client is assisted with personal care in a way that respects their dignity, safeguards their privacy and maintains personal hygiene and comfort*

day  
CARE

home  
CARE

To achieve this, DAY CARE and HOME CARE services will

- A Give personal care only where there is an assessed need for such assistance identified within the client plan
- B Assess all risks to the client before assisting with any form of personal care
- C Ensure that only competent staff give assistance with personal care tasks following written local procedures
- D Encourage the client to accept assistance in maintaining personal hygiene
- E Ensure that assistance with a personal care task does not cause additional distress
- F Inform carers and other relevant professionals about any personal care concerns
- G Ensure that assistance with personal care is private and discreet
- H Not give any non-prescribed or over the counter medicines to clients
- I Ensure that only authorised and competent staff administer prescribed medication in strict accordance with the Society's policy on the administration of prescribed medication
- J Provide suitable safe equipment for any personal care tasks undertaken

**EXAMPLE**



COLLABORATION IN A PRIMARY HEALTHCARE LED NHS

Rita Lewis, Health Research Consultant  
and Dave Cochrane, Conrane Consultancy

Rapporteurs: Chris Dabbs, Salford CHC and Beryl Furr, Southend  
District CHC

Aims.

The session aimed to identify the key features for a primary care-led N.H.S. It focused on the increased role of general practice in purchasing and providing services and the shift of resources from secondary to primary care. The session also intended to identify models of primary health care and their implications for changing service patterns, public accountability, patient representation and patient involvement.

Involving patients in the planning of care.

Dave Cochrane outlined the scenario for health care in 2005, based on a recent project. He identified the seven major structural issues as:

- \* resources
- \* N.H.S. objectives
- \* the European Union
- \* the balance between public and non-public provision.
- \* a move to more health maintenance
- \* primary care-led service
- \* ageing population and demand

The six major characteristics of health care in 2005 were envisaged to be:

- \* growth in demand
- \* a shift in centre of gravity
- \* primary care
- \* reduced use of inpatient stays
- \* some hospital site rationalisation
- \* evidence-based packages.

As for N.H.S. objectives, it was important to note the following:

- \* comprehensiveness and equity are moving targets
- \* progress requires dynamism
- \* motivating factor for staff
- \* objectives are sustainable if productivity is maintained.

Dave argued that health maintenance is important and that bad health is often a person's own responsibility. For example, of people with H.I.V. disease have innovated ideas in self-help and the gathering and distribution of information. Dave argued that the issue of responsibility can develop a useful thought process.

Dave put the issue of the increasing number of older people in the population into context. He showed that they occupy hospital beds on a hugely disproportionate scale. Their use of G.P. services is, by contrast, only slightly higher than average.

It was identified that a primary care-led N.H.S. has six main characteristics:

- \* primary care bears and manages the total resource
- \* G.P.s assume "gate keeper" roles and get an incentive to ensure efficient patient care
- \* devolution of services to primary care and people's homes
- \* improved coordination of services that are better tailored to needs
- \* clinical decisions supported by evidence-based clinical pathways
- \* G.P.-consultant interfaces based on agreed care packages.

Dave stressed that 30-40% of patients currently seen by G.P.s do not actually need to see a doctor.

The personal packages of care on which a primary care-led system rests would have nine characteristics:

- \* sets out the clinical "decision tree"
- \* evidence-based
- \* developed by local clinicians
- \* reviewed regularly
- \* held by all parties
- \* sets out care path including expected service use
- \* spans the spectrum of possible interventions
- \* patient involved in design
- \* a major element is patient/carer education.

Dave emphasised that the last two elements were essential to the process. It is important to compare what is offered against what works. Only effective care and treatment should be used. The patient will often know better than anyone else what this is. This approach would create better outcomes, reduce costs and maintain patient control.

Dave argued that mechanisms for the patient in this approach should be:

- \* information
- \* a range of options
- \* evidence including the patient's experience
- \* real influence over decisions
- \* assuming increased responsibility.

Each individual's own articulacy and confidence does, however, have a great influence on these factors. Nevertheless, in financial terms, Dave argued that the issue is not what the N.H.S. spends, but how it spends it. Patient involvement would help to ensure that it is spent more efficiently and effectively.

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### **Where are C.H.C.s in the move to a primary care-led N.H.S.?**

Rita Lewis focused on the role of C.H.C.s in a primary care-led N.H.S. She identified existing C.H.C. activities in this area as:

- \* meeting G.P.s about public contact and involvement
- \* patient satisfaction surveys
- \* promoting patient participation groups
- \* joint work with patient participation groups
- \* supporting development workers
- \* developing complaints systems
- \* linking C.H.C. members with patient participation groups
- \* working with G.P.s on commissioning.

It is essential to establish why patient participation in primary care is important:

- \* it helps patients
- \* it emphasises health education
- \* it produces self-care initiatives
- \* it informs the public on the limitations of doctors to cure and prevent illness
- \* it is a mechanism for patient feedback
- \* it provides a different G.P.-patient relationship.

Rita then reviewed the accountability of G.P. fundholders, based on a recent A.C.H.C.E.W. "Health News Briefing":

- \* 25% of C.H.C.s were involved in developing patient participation groups
- \* 10% of C.H.C.s were consulted on fundholders' purchasing plans
- \* 25% had no contact with fundholders
- \* very few C.H.C.s were sent copies of fundholders' Patients' Charters
- \* fundholding practices involving C.H.C.s were generally those that were already good practices.

C.H.C.s were seeking a range of things:

- \* visiting rights to family health services premises
- \* consultation on major changes in fundholders' purchasing plans
- \* meetings with fundholders on complaints
- \* meeting fundholding practices once a year
- \* C.H.C. attendance at the regular Health Authority/fundholder reviews
- \* fundholding practice meetings held in public
- \* publication of audits and reviews of fundholding practices.

Rita emphasised, however, that it was for each C.H.C. locally to decide how to reach this situation, according to their local circumstances.

For an effective approach, the following things were required:

- \* access to (clinical) effectiveness information
- \* an independent central resource for access to information
- \* patients able to exchange G.P. services within or between practices
- \* encouragement of proactive approaches to health promotion
- \* independent guidance to patients to exercise choice
- \* encouragement of patient feedback and good complaints systems
- \* regular patient satisfaction surveys feeding into the quality management systems of providers (monitored by purchasers)
- \* restricted access to G.P.s only in specific and reasoned situations
- \* patients regularly involved in decisions about primary care services
- \* patients as genuine partners in primary care, based on an equality of power.

Questions and comments by members of the audience, identified the following issues as needing to be addressed:

- \* "patient fundholding"
- \* C.H.C. involvement in G.P. commissioning groups
- \* the role of advocacy and representation
- \* the need to change the culture and power balance in many patient participation groups.

COLLABORATION IN A PRIMARY HEALTHCARE LED NHS

**Rita Lewis, Health Research Consultant  
and Dave Cochrane, Conrane Consultancy**  
**Rapporteurs: Chris Dabbs, Salford CHC and Beryl Furr, Southend  
District CHC**

This was one of two sessions - each apparently quite different!

Dave referred to a joint report with Manchester University exploring future NHS staffing requirements for a primary care led NHS. He addressed each area in turn: resources and rationing, NHS projects, European Union initiatives, the balance of public and non public services, the move towards 'health maintenance' and the demands imposed by an ageing population. It was the latter which would pose the greatest challenge to the NHS. At the 1991 census people over 65 represented 16% of the population but used 50% of acute beds. People over 75 represented 7% of the population but used 30% of acute beds. They used relatively few GP resources - 10% or less of the whole. However, at the same time as the number of over 75's was set to escalate, the primary care led NHS was beginning to place greater emphasis on day and short stay hospital care - with much more care at home. Patients and carers would inevitably become key players in 'health care' and NHS planning must be sensitive to their needs - not just to the planning needs of the NHS. CHCs were rightly concerned about the openness and accountability of fundholders' plans yet GPFHs and Total Purchasing Practices would exert an increasing influence on health plans. Existing measures to ensure accountability must be used to the full. Rita would talk about how, while waiting for stronger rights for CHCs, we could influence the development of Primary Care and help to ensure that patients were heard.

As 'gatekeepers' to other parts of the service, it would be in GP's interests to maintain patients in a primary health care setting, i.e. in their own homes. They must judge the effectiveness, appropriateness and quality of any hospital, community or complementary services they proposed to buy for individual patients. This would lead to structured agreements between GPs and consultants on individual packages of care which were appropriate to the needs of that patient. It would require that professionals LISTEN to the patient and/or carer right from the start to ensure their full agreement and co-operation with the plans proposed for them. An abbreviated version of Ian Carruther's 'decision tree' shows how personalised care packages might be developed:

- The clinical decision would be based on evidence of good outcomes
- The plan would be developed by local clinicians and regularly reviewed - it would be held by all parties including the patient/carer
- It would set out the care path and all the services to be provided (including those to be provided by the patient/carer) and span the whole spectrum of possible interventions
- The patient would be fully involved at all stages. The 'plan' would be a major educational tool for the patient/carer in the management of the condition

Currently the NHS chooses what services it will provide. Doctors choose from the range of services chosen by the NHS! The need for change was illustrated by 'Dave's back problem'. His GP selected from a range of services currently on offer (from painkillers and Valium to MRI scan or neurosurgery) and referred him in turn for x-ray, CT Scan and MRI. Why such an expensive, time consuming, hazardous and ineffective process? He still had his back problem! However, HIS back pain was exacerbated by headaches from coping with the problem, and other psychological and physical effects of dealing with pain. If he'd been asked what would work he would have identified the right exercise, the right osteopath, Chinese medicine and the right massage (to complement the other treatments). The outcome would be better, cheaper and leave him - the patient - in control. He could then exercise real influence in health planning by providing evidence that the treatments worked for HIM. This was what 'evidence based care' should mean. The purchasing power of GPFHs meant they could buy services which met the needs of individual patients and gave them great influence over the development of 'appropriate' services within the NHS.

He got a mixed reception! Comments included 'It's a bit like writing one's own will - frightening!' 'Older people living alone can't get involved in this sort of process. They end up in hospital because

*no one's available to help and block beds because of social services funding problems' 'There'll be sick people on the streets waiting for hospital care' etc. Dave accepted that cultural changes take time. He argued that the process needed to be supported by advocates to make sure that people got to the right services at the right time: early intervention could prevent unnecessary admissions. CHCs were uniquely placed to wake up the NHS to patients' expectations - and in so doing to influence the nature and range of services. The middle classes tended to get more out of primary care services because they exercised more control over consultations with their GP - the 'people like us syndrome'. CHCs could help to focus on the quality of the first contact with GPs and empowering people to get more out of their consultation. Advocacy Services were needed in all localities.*

The points were picked up by Rita. There was no blueprint for CHCs but many issues for discussion. Even without the much needed strengthening of the CHCs' role we could get closer to primary care teams. How? Invite GPs to talk at public meetings, undertake surveys on services and on specific issues, help establish patient participation groups, give support for Development or Link Workers, help develop practice based complaints systems, get involved in commissioning services and future plans. The benefits? It helps patients, put the emphasis on health education and voluntary activities, provides self care initiatives. It also provides patients with a realistic picture of what could be provided, invites consumer feedback and adds an extra dimension to the relationship between patients and their GPs (currently based on an average three minutes consultation).

Some CHCs were already involved: ACHCEW's report '*The Accountability of GP Fundholding*' was based on responses by 50% of CHCs of whom 25% were involved in patient participation groups, and 10% were consulted on GPFH purchasing plans. However, 25% had no contact at all with GPFHs and 40% reported their relationships as 'poor'. Few practices had Patient's Charter statements - an opportunity for CHCs. Publicity about work with co-operative GPs could be used to encourage other GPs to get involved. Hopefully CHC rights *would* be strengthened to allow us to engage directly with GP fundholders to ensure meaningful consultation and monitoring throughout the commissioning cycle. In the meantime, we could debate the action needed to improve user involvement :

- Provide an independent central Locality Resource Centre - containing national and international information about health issues, 'effective' treatments, etc.
- Campaign for patients to be able to change GPs without detriment to care - within or between practices
- Encourage a proactive approach to health promotion - to the mutual benefit of users/NHS
- Offer independent guidance to enable people to exercise choice about where to go, the track record of individual consultants, etc.
- Facilitate consumer feedback - hold regular user satisfaction surveys and feed the information into quality management systems. If not, monitor how the health authority monitors the system
- Monitor the effectiveness of the complaints procedures
- Uphold patient's rights to choose their own GP - only in specific and reasoned circumstances should a patient be allocated to a GP
- Involve users in the decision making process for primary care - if it's not being done, debate how it can be developed. Press for the sort of patient partnerships set out in Dave's presentation - recognising that there cannot be equality while GPs have the right to strike patients off their lists.
- Change the culture - GPs have historically seen CHCs as helping patients to make complaints about them. We must learn to co-operate and to promote the good aspects of the changing situation. *But stay independent - don't get sucked into the system. Think about the implications before saying 'yes'.* And remember that 'health' is all encompassing - it includes other primary health practitioners - dentists, opticians, pharmacists and non-health agencies such as social services, housing, racial equality councils, etc. All have a part to play in planning 'individual health care packages'.
- Start the debate - Patients' interests and GPs' interests may be remarkably similar - focus on enlightened self interest! Work with them to influence the development of local services and make the best use of the mechanisms open to us to make sure that users' views are heard.
- Be pragmatic! The system's here for at least the next five years. Work with it.

## DEVELOPING WOMAN-CENTRED MATERNITY SERVICES

**Session Leader: Jane Cowl, Changing Childbirth and Implementation Team**

**Rapporteur: Sally Young, North Tyneside CHC**

Jane Cowl is the Project Officer for Consumer issues for the Changing Childbirth Implementation Team. The Team brings together purchasers, providers and user representatives, to implement the 'Changing Childbirth' Report. Jane explained the background to the Changing Childbirth Report, and the influence of CHC and womens' group in influencing change. The Commission for Race Equality had produced 'Race Relations and Maternity Services'.

It is now two years into the implementation of Changing Childbirth and progress was variable around the country. All the main recommendations were based on existing good practice. The principles of Changing Childbirth were that services should be women focused, readily accessible, use resources efficiently, be responsive and involve women in planning services. The principles should be applied locally in that local services are responsive to local needs. Changes should be monitored and evaluated.

The three 'C's were 'choice, consistency and control.' Choice included - choice of professional, choice of place of birth, choice of treatment and this was dependent on INFORMATION. The nature and type of information was central. There were now a number of projects to help women make informed choices, often these were focused on particular groups of women. There were also national projects on notes held by women. One of the action points was getting the voices of service users, particularly those who did not attend traditional services. There were a variety of projects to improve consumer involvement.

Continuity included continuity of care and continuity of carer. Continuity of care included agreed protocols and guidelines. Continuity of carer was about the people involved. It wasn't always possible to have the same person, but to have a named midwife, and that the woman knows her lead professional. Pilot Projects were being done to evaluate changes. In Gloucester two different types of care were being evaluated - a traditional system and Team Midwifery.

Control included information and choices, so woman feel involved in their own care. Women were to be kept informed about what was happening, to be actively involved in decision making. Research showed this was important for all women, regardless of their class. It was important to involve users in planning and delivering of care.

Maternity Services Liaison Committees needed proper lay representation, and a lay Chair. It could be daunting for some user representatives, and could be difficult to develop relationships. Jane was involved in developing practical guidelines for supporting lay representatives. There are a number of support and training projects for user representatives (GLACHC, Critical Appraisal Skills Programme, IHS, Hull University and the NCT)

There was the key question of whether Changing Childbirth could be implemented within existing resources. Although change often had a cost, cost should not be a barrier. There may be room for redistribution of resources within the existing system eg number of visits to Consultants. A large part of Changing Childbirth was about changing attitudes. There were a number of pilot schemes which appeared to add on to existing schemes, but these should be incorporated into the total service. There were some places where there was definite underfunding of services.

There were effects on professionals. Most women would see their GP as their first contact. The lead professional was the person who co-ordinated that woman's care and provided much of that care. In some areas GPs (and Consultants) have been resistant to midwives being the lead professionals. Women can go directly to a Midwife to arrange maternity care. GPs get paid for arranging maternity care, not necessarily providing it.

There was increased responsibility and accountability for Midwives. Continuity of care means changes in terms of conditions of work. There should be a named Midwife for every woman.

Obstetrician are lead professionals for women with complicated pregnancies and women can also choose consultant-led case. This could mean increased availability.

The CC Report names ten indicators of success, these are not necessarily local targets. But CC is more than the indicators. CC is not a blue print for an ideal service - but it is important to have a flexible and adaptable service to meet the needs of local women.

There are 33 development projects funded by the Changing Childbirth Team. There is a national campaign to raise awareness among women to get them to find out more about their services and influence them. There is a computer database; a programme of conferences, support and guidance for MSLCs, a guide to information projects and working with purchasers. There were six GP Fundholders who were piloting the purchase of maternity services.



In the session that followed, members raised the following points:-

- 1) The maternity services had improved, but the Consultants and MSLC were resistant to change. The CHC had tried to support lay representatives, but meetings were changed to suit the doctors. It was suggested the Health Authority should be more involved and to use research to get professionals to understand the users point of view.
- 2) There had been changes in the MSLC - the CHC, Midwives, NCT, WI and PPA were invited to send members. There were adverts in the Press for applicants - there were women representatives of different groups. Members commented that as lay representatives increased, obstetricians decreased. There was a lay member support group.
- 3) One CHC had done a survey and still had concerns. The main problem was the role of staff on the post-natal wards and lack of support for the establishment of breast feeding.
- 4) It was not clear whether women wanted to be in hospital more than six hours. There was definitely a trend towards shorter stays, but the procedure on beds reduced choice. Some hospitals were developing hotel services.
- 5) One CHC supported an Obstetrician in the Chair of the MSLC as a way of getting better representation from doctors.
- 6) One CHC had tried to question the apparently high caesarean rates. Other members commented on the difficulties of obtaining local and national figures (See Appendix).
- 7) There could be problems when an ambulance service covered several Health Authorities and no single Health Authority would pay for the obstetric module for paramedics.
- 8) CHCs had done work on post-natal depression and were disappointed at the lack of reference to post-natal depression in the CC Report.

APPENDIX I

At the workshop I promised to send out a list of the questions we regularly ask our Maternity Hospital. These should be collected and collated, if not why not? They provide objective information, which may be useful to CHC and MSLC members. It is useful to look at developing trends.

The questions are:

1. Number of babies born
2. Total number of deliveries
3. Rate of stillbirths
4. Neonatal death rate
5. Perinatal mortality rate
6. Number of artificial ruptures of membranes
7. Number of induction of labour (by oxytocin drip or vaginal pessary)
8. Number of forcep deliveries
9. Number of ventouse deliveries
10. Caesarean section rate
11. Epidural anaesthetic
12. Number of episiotomies
13. Electronic foetal monitoring
14. Average numbers of internal examinations at Ante-natal booking clinics
15. Average number of ultrasound scans per pregnancy
16. Number of babies receiving vitamin K injections
17. Number of women receiving pubic or part-pubic shave prior to delivery
18. Number of women receiving enemas prior to delivery.

It would be useful to have a copy of the Delivery Suite protocol

SALLY YOUNG  
North Tyneside CHC

**Rapporteur: Sandra Taylor, Swansea CHC**

- 1983                      **Mental Health Act 1983**
- 1990                      **National Health Services - Community Care Act 1990**
- 1991                      **Care Programme Approach Implementation**
- 1993                      **10 Point Plan Announced by Virginia Bottomley**
- 1994                      **Supervision Registers Introduced**
- 1996                      **February      Announcement by Stephen Dorrell:**
  - a) Spectrum of Care**
  - b) 24 Hour Nursing Homes**
  - c) The Care Programme Approach Audit Pack**
  - d) Patients Charter More Money (£90 million)**
- April              Carers (Recognition & Services) Act 1995**
- Mental Health (Patients in the Community) Act 1995**

**There are 4 main elements to the CPA:**

- Mr Mehta continued his talk by referring to supervision registers which were introduced nationally from April 1994:-**

- Introduced in response to concerns that community care was not working as well as it should for most severely mentally ill people
- Intention behind the register is to identify those people with a severe mental illness who may be a significant risk to themselves or to others, and to ensure that local services focus effectively on these patients, who have the greatest need for care and active follow up
- Registers are local
- Inclusion in a register would be part of the discussion of the Care Programme before hospital discharge and subsequent reviews following discharge, or occasionally for new patients at initial assessments
- Decision is by consultant psychiatrists in consultation with other members of the mental health team involved in the patient's care

The Mental Health (Patients in the Community) Act was implemented from 1 April 1996. The main provision of the Act is the introduction of supervised discharge for patients who have been detained under the Mental Health Act 1983. It is designed for so called revolving door patients.

The new provision is available for detained patients who are not subject to the Home Office restrictions on their discharge (mainly Section 3 or Section 37 patients) and who, while no longer needing treatment in hospital, would present a substantial risk of serious harm to their own health or safety, or to the safety of others unless their aftercare in the community was supervised.

The patients subject to supervised discharge would be required to abide by the terms of his/her Care Plan (CPA).

The supervisor (most likely the key worker) will be appointed with powers to:

1. Require the patient to reside in a specified place
2. Require the patient to attend for medical treatment and rehabilitation
3. Convey a patient to a place where he/she is to attend for treatment

There is no provision for patients to be given treatment against their will in the community. If a patient did not comply with the conditions, the patient may be compulsorily admitted to hospital under the Mental Health Act 1983.

Delegates were advised of statistics that had been drawn up by the Carers Alliance Manifesto as follows:-

- 7 million people are carers
- 1.5 million carers care for more than 20 hours per week
- 20% of carers have never had a break from caring
- 65% of carers say their own health has suffered
- 70% of care is provided by family and friends
- Their contribution is worth £30 billion a year

Further statistics were given which referred to a NSF survey undertaken in January 1994

- 71% of carers had experienced problems with their mental or physical health due to their caring role
- 81% had experienced a crisis situation (where the person they care for is experiencing a relapse)
- Only 22% of carers had received written or oral information about the CPA (Care Programme Approach)
- 58% of carers said that caring had involved them in a "significant extra expense"
- For every 5 carers who want to see a psychiatrist only one does; for Social Workers and CPNs the ratio is 3:1; for GPs 2:1
- 55% of carers needed a respite break (34% wanted a holiday)
- Only 26% had ever received any information about "how to care" and only 16% had information about their rights as a relative

The conclusions of the NSF study had shown that (i) every carer has individual caring responsibilities and needs (ii) they are experts in severe mental illness (iii) they do not always want to care (iv) they have a low ceiling in terms of requests for services (v) they want to be treated as equal partners and finally they want immediate help and advice when needed.

Reference was made to the role of members of the Community Health Councils in identifying services and priorities - (a) is there enough acute beds available? (b) national standards for all aspects of services for mentally ill people (c) monitoring the application of Care Programmes and (d) are patients and carers rights honoured in relation to legislation/guidance, e.g. supervised discharge and supervision registers.

Several comments were made by the delegates:

- breaching of confidentiality
- fragmentation and accountability of services - health authority/social services
- the expectation that relatives will undertake the role of carer which places a tremendous burden on that person
- the varying degrees of care given by psychiatrists

The seminar concluded by the Chairman thanking Mr Mehta for giving what had been a very informative and interesting presentation.

SMT/PS. 30.7.97

## CARERS ARE PART OF THE TEAM

**Session Leader: Carolyn Syverson, Primary Care Development Officer,  
National Carers Association**

**Rapporteur: Celia Davies, Greenwich CHC**

### **a) Introductions**

Carolyn Syverson, Primary Care Development Officer of the National Carers Association spoke to (30+) delegates about the need for health care providers and planners to recognise carers as part of the team, particularly in primary health care, her area of expertise.

Carolyn began by providing delegates with some facts and figures on who carers are and what they do (attached). This showed the wide range of people who should be considered - from those calling in every now and then on a patient to help with cleaning or shopping, to those providing continuous care to a spouse, close relative or friend. Of particular concern were the 40,000 children who care for parents or other relatives.

Carolyn explained that her role in the NCA was to work with all primary care professionals involved in caring to advise on issues of national relevance and to represent carers on a range of policy-making bodies. Her main message was that all carers should be given greater recognition by professionals of what they do - even those giving relatively small amounts of care at present, as situations could change and they could become major carers in the future.

The amount of information that G.Ps give to carers is very variable, for instance, parents caring for a small baby with disabilities will be given far more information than will, say, the adult child caring for a parent with dementia. The family of a patient suffering from schizophrenia might be in desperate need of information about his medication etc. but concerns about the patients' own rights might well prevent this being passed on to them. Family members have no rights to much of the information they need. Carers' importance can be disregarded in order to protect the rights of patients. There is a need to get the balance right and involve carers more in a less ad hoc fashion.

### **b) What's in it for me?**

Carolyn listed the type of responses she received from G.Ps when encouraging them to involve carers more:-

1. Not enough time in the day to give carers attention too.  
But - giving advance information will actually save time spent on emergency calls because the carer is ill-prepared. Carers should insist on long enough consultations to ensure they find out all they need to know.
2. I might get it wrong (e.g. I don't know enough about social service provision).  
But - G.Ps have always had the responsibility to refer patients onto Social Services and that is all they are being asked to do now under the Carers act, not to

know all about social services provision. Perhaps the fact that the G.P/Social Services relationship is less clear-cut than the G.P/Consultant relationship is off-putting to G.Ps.

3. Carers can sue me.

But - so can anyone, though it is very difficult to sue doctors successfully. New Carers legislation still does not statutorily require doctors to take carers into account - it only recommends that this happens. The new rights refer to social services assessments.

4. They'll expect too much, like they do with the Patients' Charter.

But - as with the Patients' Charter, the Carers Act confers few substantial new rights, just more information. There may be greater expectations and/or complaints to begin with, but they will die down. In any case, carers must have their rights recognised.

5. I don't have the time to listen I'm a G.P not a counsellor.

But - listening is now recognised as part of diagnosis and treatment. If carers' symptoms of depression etc. are not heeded, there will be two patients and no carer.

6. Most carers don't want help.

True, But many don't know what help is available; may be intimidated or worried about what help means; may not want to let their loved one down - guilt is common; may be worried they will be assessed and their loved one/child etc. may be taken into care; may have to pay for necessary adaptations themselves (this is actually illegal) and, if young, may worry they themselves will be taken into care if they ask for help. Carers do have the right to decide not to help anymore.

7. I'm not allowed to give carers confidential information.

But - G.Ps can, and always have, exercised their professional judgement in such matters. As long as they can justify their own actions, on e.g health and safety grounds, they are within the law - all G.Ps know they have flexibility.

### c) Current Work

Carolyn went on to list some current projects furthering the rights of carers e.g.

Cornwall - project involving Carers workers in G.P practices to establish continuing commitment by all practice staff;

North London - survey of carers produced fact file for carers on agencies, local and national help, common health problems etc. Staff training took place and local pharmacies were involved. Now an extra carers worker is employed to oversee continuation of this work.

Home Counties - improved and increased liaison. Trust Hospital with carers of cancer patients.



Scotland - G.P practices involved in survey of needs and satisfaction leading to revised consultation procedures and better links with social services.

Midlands - G.P Survery - Carers identified and a staff member designated as a carers co-ordinator.

N. East Health Authority - Carers forum and carers involvement in local public health programmes and health promotion policy and forum.

#### **d) Outcomes**

Enough surveys now! need action; examples of good practice should be translated into policy (co-ordination/directory required); the culture of primary care must include carers.

#### **e) Questions from delegates covered the following topics:-**

- real needs v cost of addressing them affect professionals diagnosis/recommendations.
- need to speak to G.Ps as a group, not just individuals;
- how to involve G.Ps in discussions;
- Housing, Social Services, Education Services should all work together with Health Services to help carers, especially child carers;
- lack of co-operation between different departments causes problems;
- Hostels are involved in projects for young carers;
- Are spouses liable to pay for adaption (split 50/50);
- Concern re: G.Ps charging for letters to housing department, forms etc.
- Need carers contact point in G.Ps' surgeries "listening ear";
- Need for holistic approach involving all carers in family;
- Cost shunting between departments causes problems;
- G.Ps not only failing to identify carers but also those with learning difficulties who need care;
- Patients and carers also share responsibility to make views known to G.Ps;

- Discharge can be problematic where patient falsely or misguidedly claims there is no impediment to his being sent home for care;
- Child carers are a serious problem exacerbated by poor liaison between primary and secondary care;
- Tax, especially poll tax problems;
- Where patient has learning difficulties there can be special problems. Their carers may need extra help.

### f) Summary

Carolyn acknowledged that she could not cover all aspects in a one hour talk and thanked delegates for raising so many relevant topics.

The group, in turn, thanked her for a most informative session.

Celia Davies  
Rapporteur

## Who Cares?

*Carers are people who look after relatives or friends who, because of disability, illness or the effects of old age, cannot manage at home without help.*

- \* *Between 6 and 7 million people have some kind of caring role.*
- \* *Approximately 3 million men and 4 million women are carers*
- \* *Most carers are between 45 and 64 years of age - 24% of carers. This compares to 8% of the 16-29 age group, 15% of those aged 30-44 and 13% of those aged over 65.*
- \* *There are up to 40,000 children who are carers.*
- \* *38% have been caring for more than 10 years*
- \* *44% are caring for a partner, 37% care for one or both parents*
- \* *Two thirds of people caring over 20 hours per week receive no help whatsoever*
- \* *Carers receiving the least support are:*  
     *between 16 - 34 years*  
     *council tenants*  
     *those caring for people between 16 - 64 years*  
     *those caring for over 10 years*
- \* *50% of all carers of people with dementia spend more than 80 hours a week caring*

*General Household Survey 1994  
 Carers National Association Survey 1992  
 Alzheimers Disease Society Survey 1993*

## What do they do?

- \* *The support provided by carers covers a wide range of tasks. From shopping or tidying up once a week to continuous care.*
- \* *About a quarter of adult carers are involved in personal care such as washing and dressing.*
- \* *Some 20% of adult carers administer medicines and/or assist with other treatments such as physio-therapy.*

*In 1990 almost a quarter of carers were spending more than 20 hours a week caring, over 10% were spending more than 50 hours a week and these percentages are on the increase.*

*Older carers are more likely to spend long hours caring; some 45% of people caring more than 50 hours a week are over pensionable age.*

*20% of residential care admissions are due to the breakdown in care at home, specifically due to the ill health of the main carer*

*If the carers giving more than 20 hours a week of care stopped, it would cost approximately £32 billion to replace their services.*

\* **RECOGNITION**

Real recognition for who they are and what they do, their expertise and skill, their need for services. Recognition that being a carer does not mean they cease to be a person in their own right.

\* **EQUITY**

Recognition of the needs of carers should not be biased by gender assumptions, cultural differences, age, sexual orientation, race or disability.

\* **INFORMATION**

A system of clear responsibility needs to be established for signposting carers to information about benefits entitlement, medical conditions, treatments and their side effects, support groups, etc. Service providing agencies should work in co-ordination and communicate effectively with each other.

\* **CONSULTATION**

Carers should be involved in consultation through representation and direct participation.

\* **PRACTICAL SUPPORT**

Assessment procedures should be speedy, well thought out and accessible. Flexible carer focused services should be developed.

\* **FINANCIAL SUPPORT**

Less than 18% of full-time carers receive Invalid Care Allowance which is only available to first time claimants under 65. Most carers live on fixed incomes with virtually no hope of continuing or taking up employment. Many carers are asked to pay for services being given to the person for whom they are caring. Carers should be helped to access benefits, assistance if they want to work outside the home and a voice in policy regarding charges.

\* **RESPIRE CARE**

Most carers want to be carers, but it is normal for them to want time off. Allowance for this should be integrated into care plans. Information about local respite services should be available from every GP.

\* **THE RIGHT TO SAY "NO MORE"**

Caring is a relationship, and in any relationship there is change. Sometimes carers become physically or mentally exhausted to the point that they can no longer cope with the responsibility. No one should be forced to be a carer, nor should they be forced to continue if they feel they cannot.

**PATIENT PARTICIPATION AT THE SURGERY - HOW NAPP CAN HELP  
WITH THIS! SETTING UP GROUPS!**

**Session Leader: Michael Ashcroft, Chairman, National Association for  
Patient Participation**

**Rapporteur: Ben Griffith, ACHCEW**

The National Association for Patient Participation was formed twenty years ago. Membership has doubled over the last two or three years and 200 Patient Participation Groups are now affiliated. The NAPP has no paid staff and provides advice through a structure of regional officers. The Association has a roving national conference and issues a quarterly newsletter to members. The Association received a grant of £13,000 pa from the Department of Health.

There are now over 1000 Patient Participation Groups in the country and the idea is gaining ground. Around 60 per cent of groups relate to fundholding practices. Commissioning GPs are also enthusiastic about involving patients. CHCs make the case for patient involvement.

PPGs are very varied, some thriving while others are struggling. It may be sensible to see many PPGs as having a natural life of 3-5 years. A group may achieve its original objective and then collapse. PPGs need to consider the needs of all types of patients. Groups may have 20-30 members. Typical active PPG members are middle-class and middle-aged. Three-quarters are women.

PPGs should be genuinely led by patients. Some doctors may prefer a "friends of the surgery" network, or a group devoted to fundraising for the practice. It is not a good idea for GPs to choose the membership of a PPG.

It is preferable to keep formal minutes although not all PPGs do so. Typically patients, not practice staff, are responsible for the administration and minuting of meetings. If money is being handled the group will need to register as a charity.

Where surgeries have 8-10 GPs, at least one GP is likely to be enthusiastic about developing patient participation. It is never possible to involve every GP. It is important to aim to involve all practice staff including receptionists as well as the Primary Health Care Team.

At least a dozen PPGs are involved in the recruitment process to appoint new GPs. Many groups hold self-help and patient education groups on smoking or diet. A group in Peterborough runs its own health food shop in the surgery which generates funds.

Mr Ashcroft is involved in a PPG in Nuneaton which has been going for seven years. The group is now involved in discussions about how the practice's spare resources should be spent. The group's involvement in the contracting process has developed over time and they are now involved in discussions at a very early stage. The group is also trying to build up a network of patients with particular health problems who would be able to lend moral support when others develop their condition.

PPGs can bring issues to the attention of patients in a number of ways. A newsletter could be produced and displayed in the surgery. It could be included in any circulation issued by the practice and could be distributed when practice staff visit patients' homes. Very short pieces of information could be included on prescription forms. Major concerns could be raised through local newspapers. CHCs may be able to help. Meetings tend to be poorly attended. The Nuneaton practice has 14,000 patients on its list but seldom do more than seven or eight attend a meeting. However, large-scale meetings may be possible where there is a major issue like the closure of a surgery.

Links between NAPP and CHCs should be developed. The NAPP's newsletter is no longer automatically circulated to CHCs because of the cost. Affiliation to the NAPP costs £15. A pack on developing PPGs is available for £6 from PO Box 999, Nuneaton, CV11 6ZS.

## THE OMBUDSMAN'S ROLE IN THE NEW COMPLAINTS PROCEDURES

**Session Leaders: Randal Keynes, Director of Investigations and  
John Royal, Asst Director of Screening, Office of the Health Service  
Ombudsman**

**Rapporteur: Jacqueline Salter, Plymouth CHC**

The representatives from the Health Services Ombudsman at the conference workshop were Mr Randal Keynes ( Director) and Mr John Royle (Screening Manager). There were 72 participants.

The audience were issued with the new information leaflet explaining the role of the Ombudsman.

Mr Keynes commenced the presentation by saying that now is a time of uncertainty with the new complaints procedure. Only a few cases have come to them so far.(July) They also wanted to listen to the CHCs experience of how the new procedure is working and feed back this information to Sir William Reid.

After March 1996 the Ombudsman can investigate all aspects of Health Care, including professional conduct of doctors and nurses - before this was left to the professional bodies to deal with. The complaint must be received by the Ombudsman within one year from the date the person became aware of the events which are the subject of the complaint.

He cannot investigate, complaints which you could take to court or an independent tribunal, personnel issues, commercial or contractual matters, properly made decisions and services in a non NHS hospital or Nursing Home (*unless they are paid for by the NHS*), complaints about government departments and local authority departments.

If a patient is to trust the procedure, they must be assured it is independent. The Ombudsman has to be fair, adequately informed, objective, and independent. When necessary the Ombudsman will seek advice from professional advisors. Assessors will provide assistance with the complaint and report to the Ombudsman who will then make up his mind.

The Ombudsman cannot give money or get people struck off, they can give a full explanation, comment on fault and arrange a remedy.

Judgements are made by the Ombudsman who has a General Practitioner (GP) internal professional advisor and other external advisors if needed for further professional opinions. The Ombudsman puts in a draft report to the GP who has to receive it and accept the outcome. The Ombudsman then writes to the Complainant with the GP's apology. The General Medical Council will still deal with disciplinary matters (*behind closed doors*) and financial penalties can be awarded.

The power of the Ombudsman is in his Select Committee. If people do not accept the findings of their investigation they will have to argue their case with the Select committee.



Mr Royle the Screening Manager said the screening unit receives all of the complaints and he referred to the early stages of the complaint, not what happens after the Ombudsman has decided to consider the substance of the a complaint. If the complaint is within the Ombudsman's jurisdiction and if anything can be achieved for the complainant, it will either go forward as a potential investigation, refer back to the complainant for further information or to suggest further action on their part, or reject the complaint, offering reasons why.

The Ombudsman would prefer that complaints are dealt with satisfactorily at local levels and will not be inclined to investigate a complaint until the NHS complaints procedure is exhausted. *(If there are difficulties at local level you can write to the Ombudsman representative for your area to ask for help. He may write a letter to the organisation concerned enabling them to 'look again' at the complaint).* The Ombudsman will normally consider the NHS complaint procedure exhausted:

- when the complaint has been rejected in writing under local resolution
- the convenor has explained why he has rejected a written request to set up and Independent Review Panel
- when the complainant has received the report of the independent review panel and where appropriate, the decision of the relevant NHS body on the findings and nay suggestions in the report.

The Ombudsman will need to know why the Complainant is not satisfied, expressing dissatisfaction is not enough.

When presenting a Complaint to the Ombudsman:

- Include all correspondence
- Explain precisely what the complaints are
- Ensure that all parts complaints have been put to the NHS body *(if other issues are added relating to the same complaint to the Ombudsman the complaint will be referred back to be dealt with at local level)*
- Include record of meetings with the NHS body
- Explain what the complainant wants the Ombudsman to achieve for them

The average time the Ombudsman takes to investigate a complaint is 14 months. This is currently being looked at they will be setting time-limits for themselves. The work has to be prioritised, if the complainant is worried or ill please let the Ombudsman know, work can be adjusted.

CHC's are recommended to complainants by the Ombudsman, who was complimentary to CHC's for the work that they do in supporting complainants. "It is only fair and right that individuals get a full explanation"

Each Region has a contact representative at the Ombudsman's office - please ring to find out who your representative is. (A slide was shown of this, obviously not all CHC's were present) Tel: 0171 217 4051 Text Tel: 0171 217 4066.

CITIZENS' JURIESSession 1

**Ms Jo Leneghan, Health Policy Researcher, Institute for Public Policy Research**  
**Chair: David Cook, Standing Committee**  
**Rapporteur: Roselyn Wilkinson, ACHCEW**

Jo introduced the concept of Citizens' Juries. A representative group of people are recruited to the jury to discuss a local policy issue in detail and hear evidence from expert witnesses. The jury may be sponsored by a health authority and will sit for about four days. They will produce a report which is submitted to the health authority, who should respond to the recommendations of the jury.

Juries have been running in Germany for 25 years, where they consider public policy issues such as where to rebuild a cathedral. Juries have also been used in America, but they are more a media stunt. IPPR are setting up pilot juries in this country, following the German model - where the jury is tied into the decision making process. The King's Fund is involved and evaluating the IPPR studies.

CHCs have a role - Jo said that IPPR feel that the CHC needs to be involved at the start of the pilot. The health authority sets the agenda - but a model is that there should be a steering group to ensure that the issues to be discussed are 'grass roots' issues. A CHC with funding could seize the initiative or request a health authority to set up a jury to look into an issue, such as long term care.

Current health authority pilots are:

Cambridge and Huntingdon - priority setting/ role of the public in rationing decisions  
 Kensington, Chelsea and Westminster - provision of mental health services for severely mentally ill people living in the community  
 Walsall - palliative care/ building a new hospice

Juries are not appropriate to all issues and processes - it is important to ask whether it is being done for the right reasons. Involving the public does raise expectations of the people involved - and can make the health authority more accountable. IPPR have found that the public are very cynical about the motives of the health authority and recommend that the authority must be prepared to act on the decisions of the juries.

The group discussion raised a number of questions:

#### **How much do they cost?**

Juries are not cheap - one recently cost £15,000. Each juror is paid £250 to cover their costs. Jurors in one study said they didn't want to be paid in the future, as they felt a civic duty to take part. Witnesses donate their time free of charge.

#### **Are they effective?**

The question is about what happens to the decisions made by the jury. If the Walsall jury wants a new hospice, will the money be there for it to be built? What if other consultations reach different decisions about how to spend the pot of money available?

### **How/who to define the questions?**

CHCs are suspicious of the process being used as a rationing exercise. The IPPR position on rationing is that we can afford to fund the NHS, and that the health authorities should not set all the questions. CHCs have the best grassroots knowledge and should be involved.

### **Is the jury really representative?**

'The public' is a mythical creature. A time commitment of four days means that a lot of people cannot be involved in the process, but it is important that the jury is representative to be credible. IPPR appoint professional recruiters to recruit the right mix of people. The jury sits on a Monday/Tuesday and then a Saturday/Sunday so the jurors only need to take 2 days off work. The intention is that this method of consultation will reach the public who don't usually get involved.

### **Should witnesses also be chosen in an impartial way?**

When the jury report is written, the change of views of jurors, and their reasons, are recorded. Some juries are filmed so that others can see how decisions are made. It may be that CHCs should be involved on a steering group to protect against biased witnesses.

### **Are juries any more benefit than a public meeting?**

Yes - in that public meetings can be monopolised by interest groups. Juries get people involved who would never go to a public meeting - and are more like outreach work.

### **What preliminary work is undertaken to make sure the health authority will take notice of the decision of the jury?**

This is the key question - ultimately we need to see what the outcome is and whether it makes a difference on the ground. For the next pilot, IPPR have a written contract with the health authority that the health authority board will discuss the report with the jury and will give a written response.

### **What is value added - possible that with a jury the majority view will prevail?**

Juries can call their own witnesses. For instance, in KCW the jury called black mental health service users and social workers which brought up the whole issue of discrimination in the service.

### **How do you guard against people who are pushing their own prejudices?**

The selection process has to be carefully done - is the market research company good at what it does? IPPR have not had a problem with 'failed councillors' with axes to grind. In a jury of 16 people, the dominating voice can be acted on by peer pressure and mediation.

### **What happens to the jurors afterwards?**

On one project, IPPR are keeping in touch for a year to measure the outcome and value to them. In Cambridge, the health authority wants to involve them in further exercises. but if they become a standing panel they then become another panel of experts, not a citizens' jury.

**The cost is equivalent to a CHC outreach worker - is it worth it?**

Costs are being looked at - for instance to see what happens if jurors aren't paid.

**What about issues of who represents the public?**

CHCs have work to do to ensure that they do not just go along with Citizens' Juries. CHCs need to make sure that they are a vehicle for communication between the community and purchasers. How good is the relationship between the CHC and the community really?

**What is the role of the moderator?**

To guard against the jury being misled, to facilitate. IPPR have tried moderators without health policy experience, but feel that someone with experience would get more out of the witnesses.

**Is there a public gallery?**

Sometimes - this is an ongoing discussion at the moment. Some jurors feel that this would inhibit their behaviour.

PRIORITY SETTING IN THE NHS - THE RESULTS OF THE FIRST CITIZEN'S JURY

Session Leader: Jo Lenaghan, Health Policy Researcher,  
Institute for Public Policy Research  
Rapporteur: Jackie Gladden, Barnsley CHC

Jo Lenaghan explained that the Institute of Public Policy Research, a registered charity and left-wing think tank, was looking at Citizens' Juries as a project of how the public could be involved in health care decisions. A Citizens' Jury had taken place in Cambridge and Huntingdon Health Authority district and a market research company had found 16 people who were prepared to participate whose composition reflected the socio-demographic nature of the area. The company approached 76 different people to find 16 who were able and willing to be involved. The total cost of one Citizens' Jury in Cambridge and Huntingdon was £15,000 including payments of £250 to each of the jurors. The Jury had sat for 4 days and heard evidence and witnesses for and against the arguments. A report was then made to the Authority which was required to respond, and if it disagreed with the recommendations, to give the reasons why. The Jury were asked how should priorities be set, and they called their own witnesses including public health doctors, and the local CHC. They decided that the public should have a role in setting priorities but should not take the final decision. They also thought that in some circumstances quantity was more important than quality. They were then asked who should set priorities and heard from people including Philip Hunt, Director of the National Association of Health Authorities and Trusts, Professor Maurice Lessoff on behalf of the Royal College of Physicians and a Health Economist, and after considerable discussion and debate, all agreed that there should be a national body to develop guidelines for priority setting.

The IPPR was piloting four more Citizens' Juries this year, including ones on Services for People with Mental Health Problems and Palliative Care. The IPPR's view was that Citizens' Juries were just one method of involving the public. They needed to be evaluated to find out if they worked and if so under which circumstances.

In the following discussion, issues raised included;

*Are the Citizens' Juries particular interest groups?*

No, groups represent the views of the general public.

*Are the reports public?*

Yes, and at one of the newer pilots this year, the sessions will be filmed. Assessments will be made of whether or not this inhibits discussions.

*Does the Citizens' Jury work duplicate that of the CHC, take attention away from the CHC or take money away from the CHC?*

The IPPR research was not meant to replace or replicate the work of the CHC, but to look at an additional way of involving the public in decisions about health services. One recommendation from the Citizens' Jury itself in Cambridge and Huntingdon was

that the CHC should be given a lot more prominence and respect and that the CHC should be fully involved in the process.

*What would be the benefits of the Citizens' Jury?*

Shirley McKiver from the Kings Fund was evaluating the Citizens' Jury project for the IPPR and looking at which type of jury was best for which kind of problem. At present there was a lot of media publicity in the Citizens' Juries and the novelty value, and it was therefore more likely that Health Authorities would take notice of the findings.

*Perhaps the IPPR could consider carrying out a Citizens' Jury consisting of CHC members to compare it with one consisting of people recruited by a market research company.*

This might be a good idea. In the Kensington, Chelsea & Westminster district, there was going to be a Citizens' Jury looking at mental health services, but two different Citizens' Juries would be run at the same time to compare the differences in the findings and how it worked with different people. Learning from previous experience at the Kensington, Chelsea and Westminster juries, there will be a written agreement that there will be a special Health Authority meeting at which the Health Authority members would meet with the Citizens' Jury members to discuss their findings.

It was pointed out that in Germany Citizens' Juries now fitted into the decision making process and were considered in the same way as the jury service. They were used extensively by the German equivalent of Local Authorities, and the LGMB was also doing work with Local Authorities on use of Citizens' Juries in this country.

*Is it possible that Citizens' Juries might be used to legitimise rationing?*

Some CHCs were now refusing to be involved in this process and there was a danger that some Health Authorities might then bypass the CHC and set up a Citizens' Jury. IPPR were concerned that so far with Citizens' Juries, the Health Authority were setting the agenda and the questions. It was felt there could be a role for other organisations like the CHCs, to become more involved in developing the agenda to do this or for Citizens' Juries to raise their own issues.

*Could the Citizens' Jury be another layer of bureaucracy and a delaying feature of decision making?*

This was a possibility, and one which would be evaluated as part of the pilot. The Citizens' Jury was not appropriate for all Health Authorities, all issues or all circumstances, and whether or not to use the Citizens' Jury needed to be considered carefully.

*What happened to Jurors afterwards?*

Some members who had previously not had an interest in health services expressed a wish to serve as members of CHCs. Others had changed their views about particular groups in society and had started to take up voluntary work in the social and healthcare fields.

## A GUIDE TO THE INTERNET

**Session Leaders: David Crawford and Richard Clayton**

**HMSO Business Systems**

**Rapporteurs: Nigel Ellis, ACHCEW and Dilys Shaw, Ynys Mon-Anglesey  
CHC**

The session was intended to cover briefly: the history of the internet; what it can do; and how it might help CHCs.

**The Internet** is not owned or controlled by any body. There are consequently no fixed standards or rules governing its use. It was developed as a result of the US defence department wanting a de-centralised network to avoid single points of failure. The communication value of joined computer networks became clear and other organisations and academic bodies began to share their networks.

**Email** is one of the services which the internet can provide. This is the sending of textual messages to another person's computer (usually at local call rate). Email also allows you to send attachments to your message, such as a picture or a spreadsheet or a piece of software. Recipients of Email can read it and reply in reply in their own time (in much the same way as they might with a letter). Sometimes the telephone, fax or post are more convenient than Email - it is in no way intended to replace any of these.

**Security** can be a problem, although it is possible to "encrypt" sensitive information or messages. HMSO believe that suitable precautions can be taken but stress that (as with other forms of communication) security of data cannot be guaranteed.

**Newsgroups** are a means of asking questions or discussing issues with other internet users, on specific topics. Over 10,000 of these discussion groups exist on every topic imaginable and information or questions get "posted up" by users for all to see.

**The World Wide Web** is relatively new but the fastest developing aspect of the internet. It consists of graphics and text documents which are linked via "hypertext" (clicking on the text enables the user to view more detailed information). You can view information on people's web pages without having to know what machine you are linked to. This is made possible by "search engines" which allow users to "surf" the internet (the search engines actually look for the occurrence of keywords in links, which suggest that those links might hold information which is of interest).

The size of the internet is very hard to measure, partly because no-one can agree who or what actually constitutes the internet. However, it is predicted that by the year 2000, 187 million computers will be connected to it.

### **Accessing the internet**

**a) Dial-up account:** Users pay a monthly fee (possibly £10 - £15) plus all telephone charges (often local rate) for the duration of their connection. The most simple option; all that is needed is a computer, a modem, a telephone line (plus software but increasingly this is free of charge).

Some companies like Compuserve have a lower monthly charge but this increases with the number of calls made per month. Others had a standard charge per month irrespective of the use made of the service (eg Pipex, Net connection and Supernet). In order to keep the cost of calls down it was also important to bear in mind the speed at which information was transmitted and again some companies performed better at this than others (Pipex etc use faster equipment than Compuserve). Some services also had restricted access to the internet. Average costs for telephone calls, say 2½ hours per week, could be about £30 per quarter.

**b) ISDN:** Provides faster access but is more expensive to install.

**c) Leased line:** Initial installation can be thousands of pounds but users can stay permanently connected as there are no telephone charges to pay. Used for the creation of a web site (a permanent internet presence).

(Alternatively, a permanent presence can be achieved by renting space from an organisation - currently around £25 per month for 5Mb which should be sufficient for most CHCs).



## THE PRIVATISATION OF LONG-TERM CARE

**Session Leader: Anne Davis, Trainer and Consultant in Community Care**  
**Rapporteur: Angeline Burke, ACHCEW**

The aim of the session was to examine the changing CHC roles and relationships with private sector providers who have NHS contracts, focusing on the outcomes for service users - including the quality of care.

The topic for the session was obviously of interest to CHC members and staff and was well attended. The session moved at a rapid pace with numerous contributions from the participants. The speed of the debate, however, made it difficult to keep track of all the points raised. What follows is a summary of some of the main points raised.

Anne Davis started the session by describing the growth of private institutional care in contrast to the sharp decline in numbers of NHS long stay beds. The decline had reached the point where some health authorities had no long stay beds for elderly people. In 1993 there were 155,000 public sector long stay places for elderly and chronically ill people and almost 400,000 private and voluntary residential and nursing home beds.

**Q** Has privatisation led to improvements or simply replaced small institutions with larger institutions?

**A** In health care a number of big companies have become involved and some have sites with large numbers of beds. Individuals have become commodities rather than users of services. The priorities of many companies are not user focused.

In the current situation it is difficult to unscramble the public/private mix. For example, there may be public funding with private supply, private funding and supply and contracts for beds with the private/voluntary sectors. Whatever the mix it is important that all provision is of a high standard and that the quality of life for residents is good. The private sector is often berated for poor standards and quality of care but unacceptable standards can also be found in some NHS provision. If standards in private homes are to improve we must look at:

Low staff numbers: staffing levels are at crisis point - nurses cannot be shared between homes but this was possible when care was hospital based. If more staff are employed in the community people could remain in their own homes.

Low wages.

Increasing dependency levels in nursing homes: homes are becoming more mechanical eg use of lifting equipment, rather than personal care.

Staff training.

Record keeping.

**Q** Would there be the temptation to put people in residential homes (rather than nursing homes) because they are cheaper?

**A** It is illegal to place people in a residential home if on the day of admission they require nursing care. However if a resident should become ill in a residential home they can receive nursing care on a short term basis.

**Q** How can CHCs improve the quality of life in the independent sector as they did in hospitals?

**A** CHCs can press for reports of inspections to be open, as is the case for inspections of residential homes. Open reporting will expose low standards. Lay people want good standards of care not just legal minimum standards. Inspection reports need to include information about technical issues concerning quality but users want information concerned more with quality of life issues. Open reporting allows an overview and technical information can be followed up as necessary. CHCs can become involved in inspections as lay assessors. Contracts are useful for raising standards as long as they do not contradict the law and guidelines. CHCs can become involved in contract setting and the monitoring of attainment. CHCs can push things in the right direction not necessarily change them.

### Standards

It is difficult to set standards because of the differing perceptions of what is good quality care. One way of imposing some discipline on the ideas about the content and measurement of quality has been suggested by Donabedian (1980). He distinguishes between **structure** (number and calibre of personnel, quality of buildings, equipment etc.), **process** (the way the resources are used) and **outcomes** (the benefits to the patient). **Output** has been added to distinguish between those substantive measures of quality of care, staff turnover, number of accidents, deaths, outbreaks of infection or skin care - and the less tangible assessments of satisfaction, comfort and well-being. Standards of good practice should include aspects of all four elements. For example:

Dignity	→	outcome
Independence	→	output
Privacy	→	process
Fulfilment	→	outcome
Rights	→	input
Choice	→	process

Inputs and outputs are generally technical and measurable.

Processes and outcomes are important to individuals and may change when CHCs and others are visiting.

**General comments**

Quality is a measure of equity. Public funding should be related to need.

When long stay accommodation was available in hospitals rehabilitation was available. There is now concern that rather than receiving rehabilitation people are discharged to nursing homes where they remain. If rehabilitation is available people might be able to return to their own homes rather than institutions.

If homes are poor there is no alternative provision because of the reduction in NHS provision.

Moving inspection away from health and local authorities may prevent issues such as conflicts of interests arising ie moving inspection to a completely independent body.

In Liverpool when inspectors are going out they take a non-executive director or ask a CHC member to join them on their visits.

Privatisation has put money into what until fairly recently was a 'Cinderella' service. In good homes there is a lot going on.

Improvements are possible through the general application of accepted good practice. Quality is improved by paying more attention to outcomes of care, in which performance and patient preferences are accorded centre stage.

## WINDOWS 95 AND OFFICE 95

**Session Leaders: Andy Lund, Software Corporation and  
Robert Moore, HMSO Business Systems  
Rapporteur: Dilys Shaw, Ynys Mon-Anglesey CHC**

Rob Moore gave a comprehensive overview of the problems of COMPUTER VIRUSES. In terms of basic security most large companies work to the standards of BS 7799 - Confidentiality, Integrity, and Availability. If any of these are lost the work is affected and he therefore advocated small organizations also should be aware of, and implement, similar principles - at the very least regular backups of files should be carried out and the disks stored outside the office. ( e.g. Chief Officers' homes).

The main security risks consisted of RAM raids (theft of computers or their components): INTERNET (mainly affecting large companies) and VIRUSES. The latter probably presented the greatest risk as the number of viruses in circulation was increasing daily (about 200 a month). To date at least 8,500 were known.

COMPUTER VIRUSES were defined as a piece of computer code which was self replicating once attached to software already installed in a computer (Hence the similarity to biological viruses). Its presence meant that it brought about a change in the execution of existing software. Depending on the type of virus present it was not always immediately obvious that it was present since they were triggered by specific events (e.g. Dates etc.). Some viruses acted slowly, other more rapidly, some only resided in the Computer memory and could be removed, others were non memory types. In recent years Boot sector viruses were the most popular (actioned when a computer was switched on and programs booted). Parasitic viruses were obtained by copying infected programs. Other viruses were a hybrid of both the above. Yet another type was the MACRO virus associated with the Winword concept. The effects of the presence of a virus could vary from minimal (perhaps slower operation of a computer) to devastating, when all data was lost and requiring replacement of processors, hard disks, CD ROM's etc. Also viruses could be transmitted via networks, exchange of discs (perhaps from another computer at home), by E Mail etc.

In recent years a whole new industry has been spawned by viruses - as soon as viruses are written more software has to be produced to screen computers for them. One of the key players is DR Solomon who produces such a 'tool kit' - but only for about 150 of the main viruses. A more reliable (but more expensive) option is the SOPHOS SWEEP virus detection software which covers all know viruses and updates this every month. In spite of the Data Protection Act and the Computer Misuse Act it would appear prosecutions against Virus producers are not common. In the meantime, CHCs are recommended to exercise caution regarding what disks are used and shared, and if at all possible, to acquire virus screening software.

## WINDOWS 95 AND MICROSOFT OFFICE 95

Andy Lund reminded delegates that ACHCEW now had an agreement with HMSO which enabled all CHCs to purchase software at discounted rates and a price list was available at the conference

The main differences of working with Windows 95, now a 32 bit operating system, were discussed - not least the ability to work easily with several applications at the same time, as well as greater speed and interactiveness. The main new features of all the Microsoft Office applications were itemized - e.g. Word - answer wizard and several automatic features for text correction, headings, bullets, borders, fractions etc.

Powerpoint also had many new features such as multiple 'undo', style checker, auto correct, auto clipart, new slide show tools, and multimedia capabilities.

Excel had several new features including Auto answer, automatic complete, correct, filter. The 'Drag and drop' facility was also improved

## DEVELOPING PRIMARY CARE FOR BLACK AND MINORITY ETHNIC PEOPLE

**Session Leader: Professor Michael Chan, NHS Ethnic Health Unit**  
**Rapporteur: Roselyn Wilkinson, ACHCEW**

Professor Chan opened the session by reviewing the remit of the Unit:  
 The NHS Ethnic Health Unit was set up in 1994 to run to 1997:

- to secure greater benefit from the NHS for minority ethnic people through working with NHS trusts, GPs and GP Fundholders, through the development of purchasing and the implementation of major health policies.
- promote the voice of minority ethnic groups in the commissioning and delivery of services
- promote partnership between health authorities and local minority ethnic groups
- aims to secure health authority commitment to this work and to incorporate successful local schemes into mainstream services

By 1996, the Unit has project funded 123 projects costing £3 million. All projects must be co-signed by a local head of an ethnic group.

In terms of primary care work, the Unit has published a Good Practice Guide for health authorities and GPs (copies available free of charge from NAHAT). This includes primary health care quality indicators such as:

For primary health care providers-

- what steps are you taking to discover your practice profile?

and for health authorities-

- what mechanisms are in place to assist GPs in determining their practice population?

To further their work in primary care, the Unit has run focus groups of minority ethnic people to determine their concerns about primary care, and met with GPs to gather their concerns.

The concerns of the community:

- difficulties in registering with GPs because of limited knowledge and complex form-filling
- inadequate consultation time with the GP and inadequate explanation of treatment and drugs
- inappropriate prescribing
- difficulties in being transferred to other services

To alleviate these difficulties, they recommended:

- peoples' rights to GP and primary care services should be publicised
- information on rights to complain
- greater use of video and outreach

## **Developing Primary Care for Black and Minority Ethnic People: contd.**

- professionally trained interpreting services
- improved co-ordination of referral systems between primary and secondary care
- appropriate mechanisms for obtaining the views of black and minority ethnic people
- the introduction of ethnic data collection on languages spoken, religious beliefs, take up of services and referral patterns

The GP perspective:

Fifty single-handed GPs from Bradford, Leicester and Newham voiced their concerns-

- lack of time and resources for health promotion
- negative patient attitudes to chronic illness and health promotion
- communication and language barriers
- lack of proper understanding of cultural issues
- patients fail to consult for serious chronic illness
- difficulties of access - language problems and lack of knowledge about the GPs role

They recommended:

- improve patients awareness of services available
- importance of health promotion and alternative approaches to minor illness
- keeping healthy in tropical countries
- better information on how to complain, how the system works, when to consult your GP, services available including advocacy
- all information should be in simple English and other languages

Professor Chan concluded that the work of the Unit will continue, even after the Unit goes.

### Group Discussion

**How many projects were GP generated?** 5 or 6 out of 123.

**How can CHCs get feedback about these projects?** Write to Professor Chan and he'll make sure the health authority gives out information.

the group went on to discuss the short term nature of 'ethnic' projects - often with only one years funding. The Unit wants to monitor how health authorities keep up this work - CHCs can help with this, and try to ensure that health authorities take this work seriously.

in many areas, the numbers of people in any minority ethnic group are small, and the population isolated. In these areas, it is even more important that GPs are aware of cultural differences, and CHCs need to try harder to get in touch with these small groups.

CHCs can share good practice, for instance about outreach work. Also explore funding opportunities. It is possible to involve other agencies such as the Police, Social Services (start with the Director), Commission for Racial Equality etc. and take a multi-disciplinary approach.

## BY ACCIDENT OR DESIGN - IMPROVING A & E SERVICES

**Session Leader: Ian Jones, Project Manager (Health Studies), Audit Commission**

**Rapporteur: Nigel Ellis, ACHCEW**

The Audit Commission is responsible for the national reports which precede local audits of the NHS. These reports are subject to wide consultation, and focus on those areas of the NHS which are under pressure and which have a significant impact on the public.

The Commission's recent report *By Accident or Design* looked at Accident & Emergency services under the following headings:

1. Waiting for treatment
2. Minding the quality
3. Working with other specialties
4. Looking to the future

### ***1. Waiting for treatment***

The Audit Commission looked at why Accident & Emergency services are under pressure. The number of new attendances is rising each year but the real pressure is from emergency admissions, many of which are not emergencies - they just pass through Accident & Emergency.

What improvements do patients want? Primarily, patients want **shorter waits**. The Audit Commission found that those Accident & Emergency units best at meeting the Patient's Charter standard (to be seen immediately and have need for treatment assessed), did not correlate with those which provided the quickest treatment. The Commission believes that it is the time taken to see a doctor (or nurse practitioner) which should be recorded and published.

**Staffing** has increased in recent years but there are still shortages - particularly in the number of SHO equivalents. One solution is through the use of emergency nurse practitioners (even though these are more costly) and giving more attention to rostering.

If patients are kept well **informed**, long waits can be more "bearable".

### ***2. Minding the quality***

There are huge variations in the length of time that a "**more experienced**" doctor is present at Accident & Emergency - 60% of units only have one Accident & Emergency consultant.

There are deficiencies in the information which is provided to GPs following **discharge**. Frail patients are often discharged without next-day visits to check how they are coping.



Most units have a separate treatment room for **children** but less than half have a separate waiting room. Some childrens' units are staffed only 7 hours per day, and 40% of Accident & Emergency departments have no Registered Sick Childrens' Nurses.

**Psychologically disturbed patients** should be cared for by specialist staff in separate facilities but often are not. In addition to this, many units have no policy on the care of anxious or **bereaved relatives**.

### **3. Working with other specialties**

Many Accident & Emergency units could not deal with seriously ill or injured patients outside normal working hours. This situation could be improved by timely back up from other specialties.

The Audit Commission recommend that a senior manager should introduce initiatives to reduce delays in emergency admissions but that there should be joint responsibility for these by other hospital specialties.

### **4. Looking to the future**

Accident & Emergency services are under great pressure but there are also many opportunities to make improvements (developing nursing, GP referral direct to hospital etc). The Audit Commission believes there could be advantages in using fewer, larger Accident & Emergency units (although this would obviously restrict access to services by patients). The conclusion is that the smaller units should be reviewed where there exists access to alternative major units.

Q. Do local auditors contact CHCs?

A. They should do.

Q. Did the Audit Commission take the length of time to get to Accident & Emergency into consideration?

A. No

Q. How was discharge audited?

A. By looking at the unit's discharge protocol.

Q. Is there not some cynicism about figures used in audits when they have been provided by the unit itself?

A. The Audit Commission use large samples over long periods and therefore have to rely on data provided by hospitals themselves. However, validity and credibility checks are made.

Q. How many emergency admissions are actually re-admissions?

A. Research (commissioned by the NHS Trusts Federation) suggests that this is not a major issue.

Q. How can CHCs get involved with local audit?

A. CHCs are supposed to be consulted before local audits. However, the audit reports are not published and the CHC has no right to see them.

### THE COMMISSION'S OBJECTIVES FOR 1996-2001

- Helping with change
- Focusing on the citizen
- Strengthening accountability
- Improving the impact of local audit and the Commission's effectiveness
- Promoting high standards of public audit
- Working in partnership with others

A·U·D·I·T  
COMMISSION

A&E  
audit

### BY ACCIDENT OR DESIGN

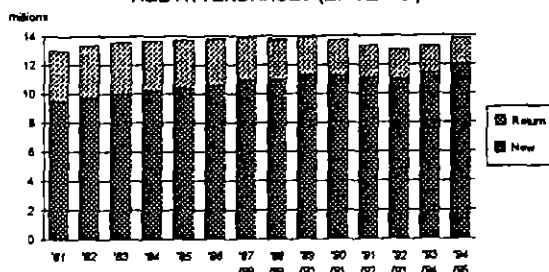
1. WAITING FOR TREATMENT
2. MINDING THE QUALITY
3. WORKING WITH OTHER SPECIALTIES
4. LOOKING TO THE FUTURE



A·U·D·I·T  
COMMISSION

A&E  
audit

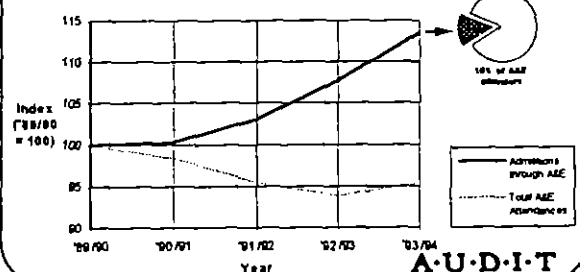
### A&E ATTENDANCES (ENGLAND)



A·U·D·I·T  
COMMISSION

A&E  
audit

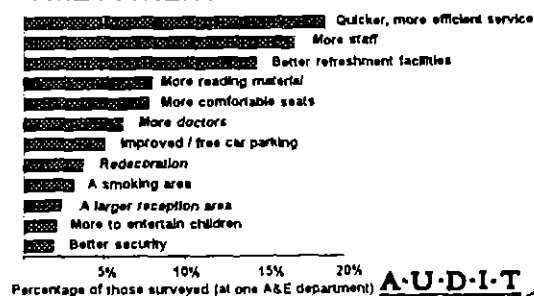
### TRENDS IN EMERGENCY ADMISSIONS THROUGH A&E



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COMMISSION

A&E  
audit

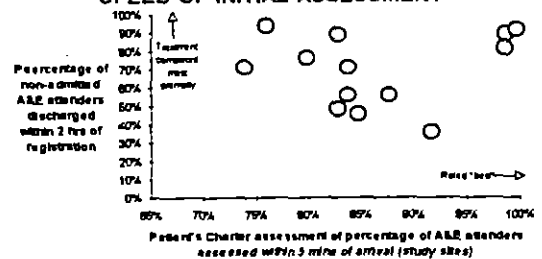
### WHAT IMPROVEMENTS A&E PATIENTS MOST WANTED



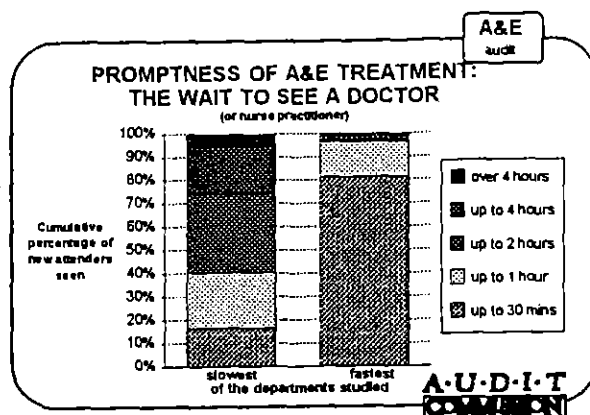
A·U·D·I·T  
COMMISSION

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audit

### DELAYS IN TREATMENT COMPARED TO SPEED OF INITIAL ASSESSMENT



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COMMISSION

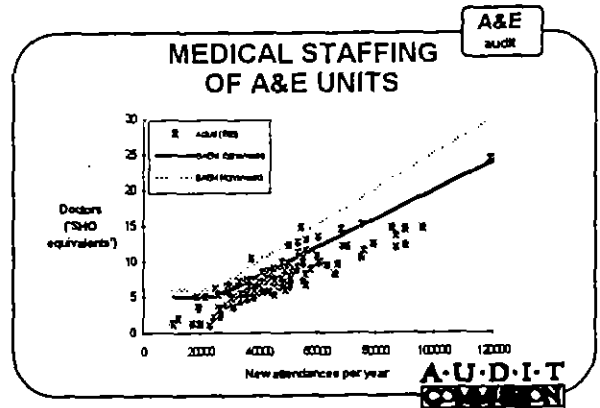
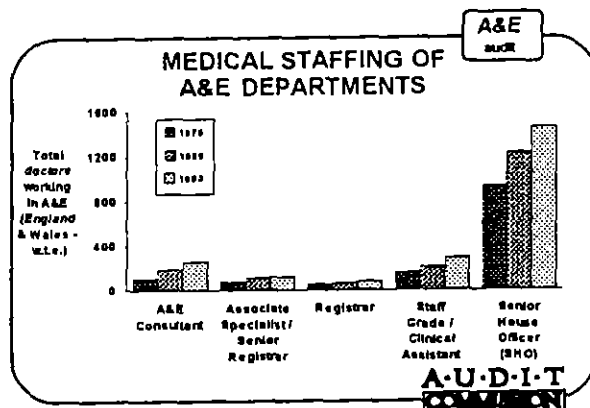


A&E  
audit

### BY ACCIDENT OR DESIGN

1. WAITING FOR TREATMENT
  - Establishing meaningful targets
  - Reducing congestion in A&E
  - Coping with the demand:
    - role development
  - Improving rostering
  - Better management information

A.U.D.I.T  
COMMON

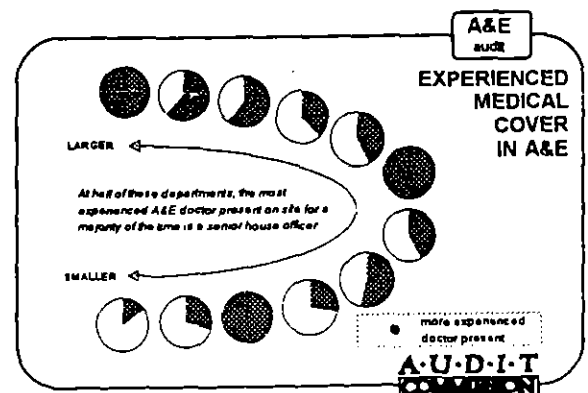


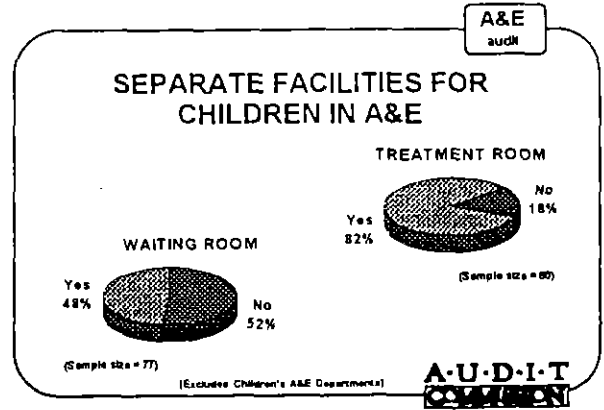
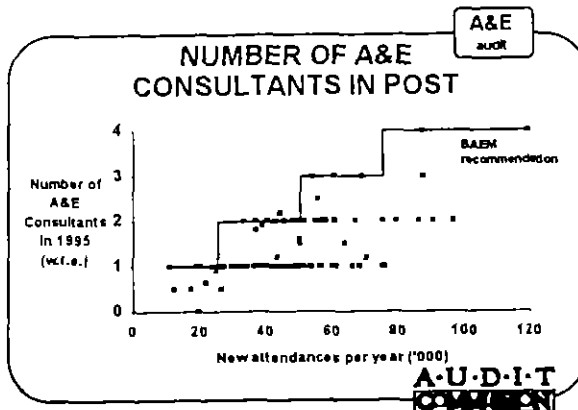
A&E  
audit

### BY ACCIDENT OR DESIGN

1. WAITING FOR TREATMENT
2. MINDING THE QUALITY
  - Developing clinical competence
  - Smooth discharge from A&E
  - Treating the potentially vulnerable
  - Finding out users' views
3. WORKING WITH OTHER SPECIALTIES

A.U.D.I.T  
COMMON



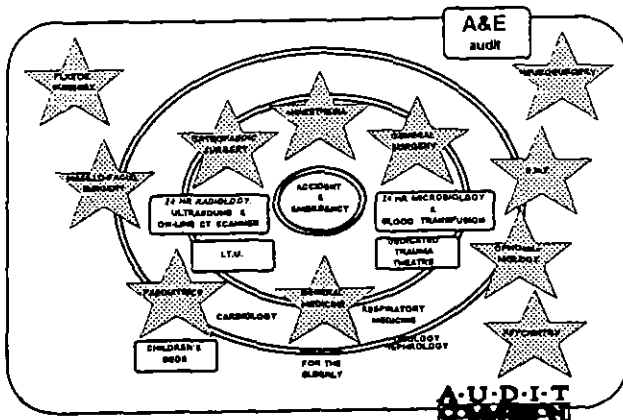


- A&E  
audit
- ### CHILDREN IN A&E (2)
- Some children's A&Es are staffed for only 7 hours a day
  - Not enough sick children's nurses:
    - 40% of A&Es have no RSCNs
    - only 20% have more than one
    - < 2% have enough for one on each shift
  - Some A&Es are not supported by on-site paediatricians
- A·U·D·I·T  
COMMISSION

- A&E  
audit
- ### CARE OF PSYCHOLOGICALLY DISTURBED PATIENTS
- Separate crisis intervention centres for mentally ill patients
  - Psychiatric liaison nurse to assess patients and organise swift referrals
  - Training for A&E staff
- A·U·D·I·T  
COMMISSION

- A&E  
audit
- ### CARING FOR ANXIOUS OR BEREAVED RELATIVES
- A written policy and procedures
  - Staff to care for relatives and keep them informed
  - Somewhere for relatives to wait in privacy
  - Appropriate follow-up
  - Staff training, debriefs and audit
- A·U·D·I·T  
COMMISSION

- A&E  
audit
- ### BY ACCIDENT OR DESIGN
1. WAITING FOR TREATMENT
  2. MINDING THE QUALITY
  3. WORKING WITH OTHER SPECIALTIES
    - Access to specialist advice
    - Speeding inpatient admissions
    - Treating the severely sick or injured
- 
- A·U·D·I·T  
COMMISSION



### STABILISING THE MOST SEVERELY ILL PATIENTS

One major A&E studied had:

- NO anaesthetic cover out of hours
- NO ITU or ventilated beds on site
- NO middle grade or senior A&E doctors on site out of hours
- NO middle grade or senior physicians on site
- NO paediatricians on site
- NO routine A&E audit

A&E  
audit

A.U.D.I.T  
COMMISSION

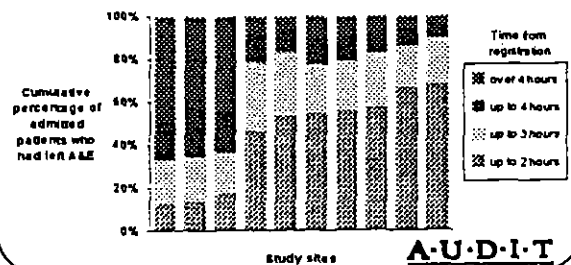
### TREATING SERIOUS INJURIES

- Co-ordination of A&E and pre-hospital care
- Swift response by experienced staff
- An effective team approach with common training and agreed protocols
- 24 hour diagnostic services (eg, CT scan)
- Availability of urgent theatre slots and on-site intensive care
- Inter-hospital audit

A&E  
audit

A.U.D.I.T  
COMMISSION

### EMERGENCY ADMISSIONS: TIME SPENT IN A&E



### EASING THE ADMISSIONS LOG-JAM



Change the pattern  
of GP emergency referrals  
by providing.....

- open access to tests and x-rays
- opportunities for GPs to ask consultants' advice
- emergency slots in out-patients

A&E  
audit

A.U.D.I.T  
COMMISSION

### REDUCING "TROLLEY WAITS"

Allocate responsibility for promoting and co-ordinating initiatives to one senior manager

Audit the scope of the problem and when it occurs; seek patient views

Establish 'joint ownership' of the problem

Determine the principal causes of delay

Poor bed  
availability

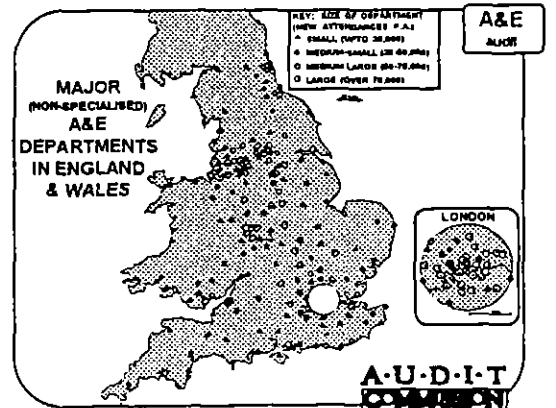
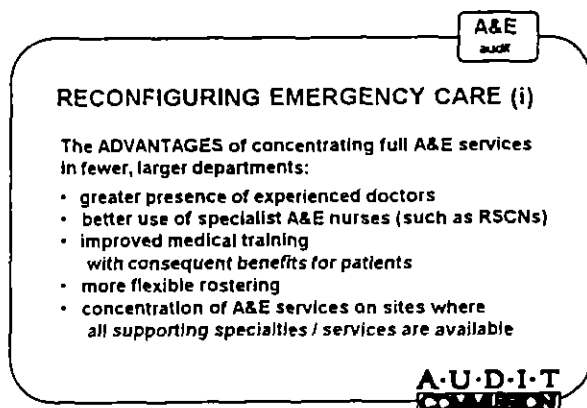
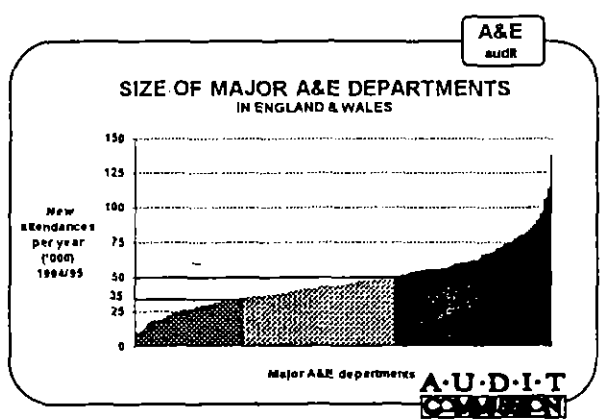
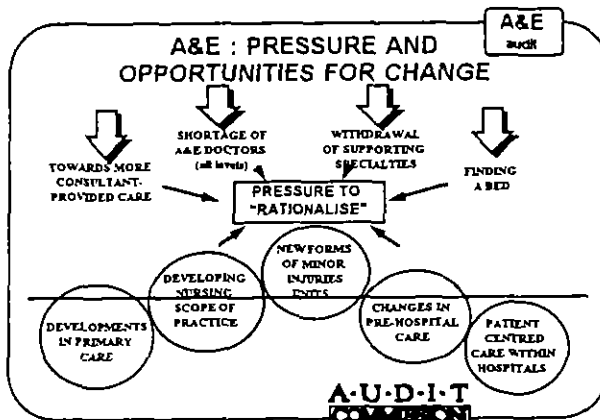
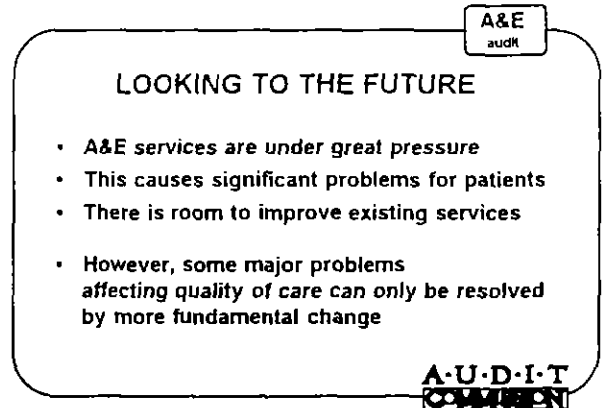
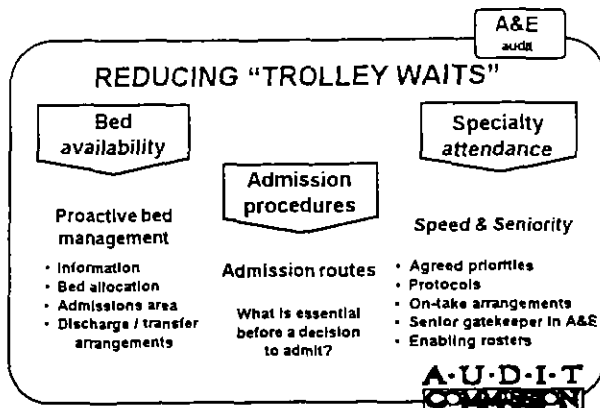
Slow attendance by  
doctors able to  
authorise admission

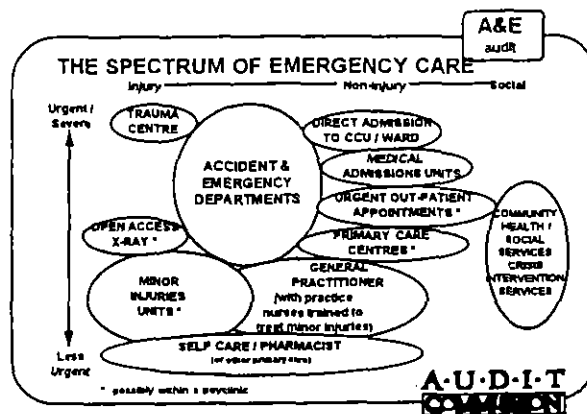
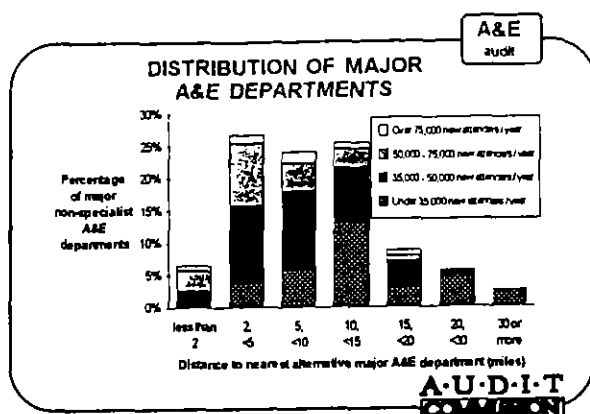
Slow diagnostic  
or support services,  
portering/transport

Inefficient  
admission  
procedures

A&E  
audit

A.U.D.I.T  
COMMISSION





**A&E**  
audit

### PRE-REQUISITES FOR A&E RATIONALISATION (i)

EVIDENCE

INTEGRATED PLANNING

PUBLIC & CLINICIAN SUPPORT

**A·U·D·I·T**  
**COMMON**

**A&E**  
audit

### PRE-REQUISITES FOR A&E RATIONALISATION (ii)

- An alternative A&E location with better 24 hour access to supporting specialties / services
- Adequate access to theatres, ITU & beds for remaining A&E departments with increased demand
- Review of emergency admission arrangements
- Assurance of effective ambulance services
- Alternative local facilities for treating minor injuries and out-of-hours medical emergencies

**A·U·D·I·T**  
**COMMON**

**A&E**  
audit

### PRE-REQUISITES FOR A&E RATIONALISATION (iii)

- Consideration of the impact on hospitals which would lose their A&E
- Focused patient & parent education to reduce demand
- An effective communication strategy
- Post-evaluation of effects of the changes on
  - local care access and use
  - waiting times
  - quality of care
  - total NHS costs etc

**A·U·D·I·T**  
**COMMON**

## AS A 'COMMUNITY' HEALTH COUNCIL, DO WE REALLY INVOLVE OUR COMMUNITY?

Session Leader: Norma O'Hara, Mid Essex CHC

Rapporteur: Pat Heath, Rotherham CHC

1. The Chair welcomed delegates to the session and introduced Norma O'Hara, Chief Officer from Mid-Essex CHC who was to lead the workshop presentation. He also informed delegates that the OHP slides used in the presentation, plus accompanying material, were available in an information pack which would be supplied on request if there were insufficient copies available that morning. He asked that interested parties should leave relevant details in order that packs could be forwarded to the appropriate addresses. (Copies of the slides are attached for information).

2. Ms. O'Hara based the presentation on the experiences of Mid-Essex CHC which had developed the concept of "Cluster Groups" in an attempt to involve more closely the views of local communities in the work of the CHC. In summary, she explained that the Cluster Groups were:

**\* Developed as a means of the CHC responding to the diverse needs of local communities in the district, which has a mix of urban and rural settings;**

**\* Originally eight in number, now extended to eleven, and comprising an average membership of ten people from the local community, including members of the CHC. Groups were based on distinct communities, with membership drawn from a range of local people who had expressed a strong interest in offering views on health-related issues. The groups were serviced by CHC officers and determined their own agendas in terms of meeting arrangements, issues for discussion, etc.;**

**\* Funded by the local Health Authority, initially for £5000 for the first year, subsequently renewed for an additional year to the tune of £8000. The funding covered items such as travel costs, room hire, and cost of carers (where appropriate).**

**\* Attempting to find ways of incorporating GPFundholders into the Cluster Group arrangements.**

3. Following her presentation, Ms. O'Hara invited questions. The main points raised were as



follows:

**i) Q: Is training necessary for cluster group members, and is any provided?**

A: Training has not been identified as an issue by members, as the groups are serviced by CHC officers who provide the necessary administrative support.

**ii) Q: Has the establishment of the groups had any implications for CHC staffing?**

A: In view of workloads, staffing is always a problem in CHCs. The development of the groups has been seen as a priority by the CHC and workloads have been managed accordingly within the existing staffing establishment of 3 W.T.E.

**iii) Q: Have greater difficulties been encountered in establishing groups in urban, as opposed to rural, areas?**

A: There has been no noticeable difference experienced.

**iv) Q: Is there any evidence that the use of the groups has changed the policies of health agencies?**

A: This is always difficult to ascertain precisely, but there is some evidence to suggest that local draft policies on NHS Continuing Care arrangements were amended as a result of the views of the groups and activities they were involved with, such as a carers conference organised jointly by the local Health Authority and Social Services department. There were also other examples of changes brought about as a result of views put forward from group discussions, so it was possible to demonstrate that the groups activities had been influential with local health agencies.

**v) Q: Have any G.P.s become involved with the groups? What has been the reaction of G.P.s generally to this development?**

A: As yet, G.P.s are not involved with the groups. However, each group is making attempts to secure representation from local G.P. practices. The response from G.P.s has been quite variable, with some apathetic but others supportive.

**vi) Q: Who decides the groups' topics and programmes? How is the conduct of the groups' business carried out?**

A: The groups themselves decide their own agendas and issues, based on local factors and circumstances. Some issues, such as Health Authority purchasing intentions, Community/Continuing Care issues, will be common across groups. Each group includes at least one active CHC member, whose role is to facilitate discussion and group business. It is the intention to try and ensure that the discussions tie in with the NHS business and planning timescale framework.

**vii) Q: How is the issue of confidentiality addressed within the groups?**

A: Confidentiality is primarily respected through the groups not dealing with "casework". Individual complaints are not discussed within the group setting. Any case-studies, involving themselves, which are brought forward as examples by group members are always anonymised if they are to be used outside the group. The approval needs to be sought from group members prior to documents being circulated outside the group.

**viii) Q: Have there been any difficulties including members of minority ethnic communities**

**within the groups?**

A: Some problems have been encountered and this is something which groups, and the CHC, are trying to address. However, there do not appear to be any magic solutions to this issue and the CHC would welcome any suggestions or successful examples from elsewhere. (For information, one delegate suggested that the Greater London Association of CHCs had produced a checklist which may be helpful.)

**ix) Q: Is there a process for review, and how are members kept motivated?**

A: Progress is reviewed on an annual basis and group membership was initially to be for a twelve month period. As mentioned earlier, there is some evidence to show that the groups' activities are influencing local health policies and practice and that in itself is a motivating factor for group members. This has been shown by the fact that there have been a number of requests from members to extend the period of group membership from one to two years.

**x) Q: In terms of influencing change, was the Health Authority contacted in advance to see if it had any specific issues on which it wanted the views of local people?**

A: No! In funding the group framework, the Health Authority was not prescriptive about issues and adopted a "bottom-up" approach to the process. Consequently, the Health Authority has been presented with issues identified by local people as being of concern, which in itself has been regarded as informative. In addition, the process is not just about how to develop new services or what to spend money on if it becomes available. It is as much about influencing change through examining existing working practices and procedures and offering views as to how these can be improved, through more effective use of existing resources. As a consequence, groups are now finding that they are receiving offers from local health professionals to come and discuss with them ways of improving existing working practices, sometimes with no financial implications whatsoever.

**xi) Q: How are disadvantaged groups reached?**

A: Attempts are made to focus on people who don't usually attend meetings and who are not empowered. This means that alternatives to the traditional type of meeting arrangement need to be explored. Group meeting arrangements are organised by the groups themselves, with meetings being held in locations where members feel comfortable. These include a range of venues, such as pubs, members homes etc. In addition, surveys undertaken by the CHC complement the views derived from the work of the groups in ascertaining the views of particular "target" groups.

4. Following this discussion, the Chair thanked Ms. O'Hara for her presentation and also thanked delegates for their contributions, which had been extremely encouraging. He valued their attendance and hoped that they had found the session helpful in discussing one way of developing this key area of CHC activities. Mid -Essex CHC would be willing to provide further details of this initiative on request. With that, he concluded the session.

## Cluster<sup>77</sup> Groups

An idea which arose from a meeting in a local pub has gone on to become a well acclaimed established form of consultation.

Mid Essex Community Health Council developed the idea which the Health Authority agreed to financially support for a year.

This network had eight groups, now 10, of people with each group representing a specific small geographic area covering a cluster of neighbouring parishes. membership of these cluster groups consists of three CHC members and seven residents from the cluster area.

The membership criteria for residents joining the cluster groups is that they should be active in the community, but not already serving as a local authority member. The local grapevine is the key process for identifying potential volunteers and also acts as the main medium for business once the groups get started.

With the cluster groups having a time limited involvement of 12 months, this gives volunteers a clear view of the extent of their role and avoids the possible longer term effect of complacency becoming a factor. The groups seek out local views on health care from their neighbours, friends, customers and colleagues. They also provide a forum for consultation on specific issues: continuing care policies.

The groups meet quarterly, but the real discussion takes place between meetings - at home, in social gatherings or at work.

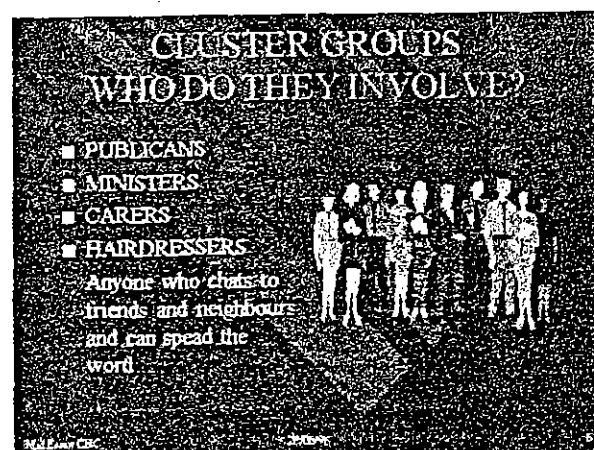
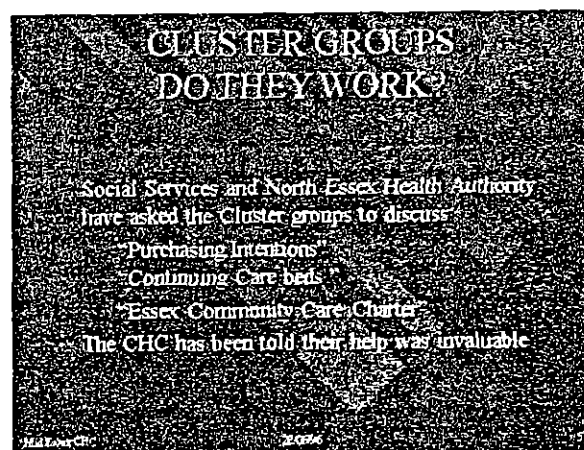
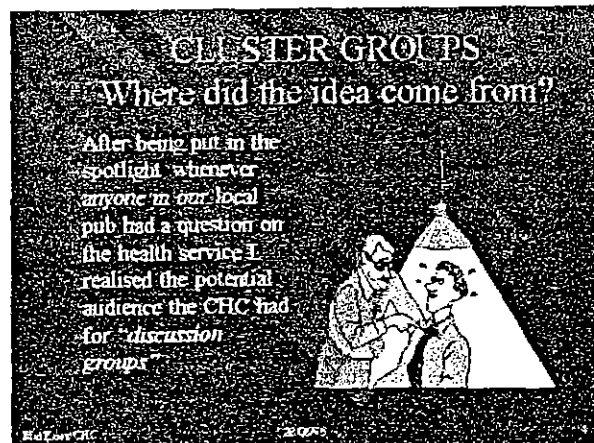
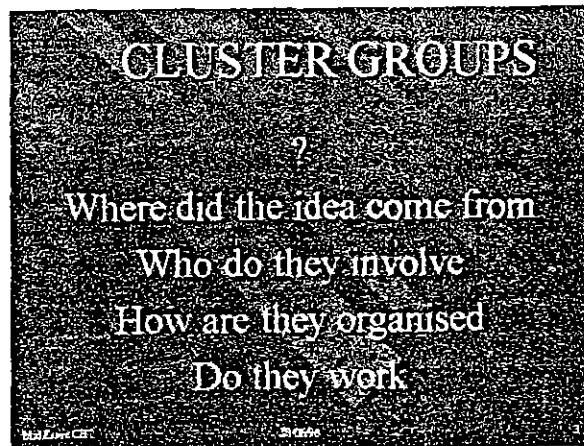
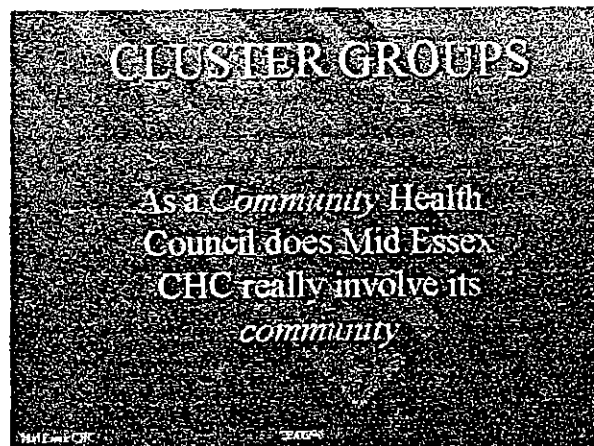
Cluster group meeting dates have now been included as part of the health authority's and Social Services purchasing cycle:

July	Cluster groups begin discussions on Patient's Charter Standards
October	Views fed into initial purchasing intentions
January	Cluster groups discuss purchasing plans and future strategies
May	Final meeting, in the form of a conference, reviews the years outcomes with all the cluster groups, together with local health and social services policy makers.

This work has proved highly successful and the Health Authority has continued its support for 1996/97.

### *Why the pilot is working*

- \* The public are getting the help they need to get involved in health decisions.
- \* Help is from the Community Health Council , with the health authority at arm's length. The scheme itself, therefore remains unbiased and independent.
- \* Such a direct link to the health purchasing plan, health strategy and individual issues, assures the public of having a genuine influence on health decisions in a way that is compatible with the health authority.
- \* The commitment expected of volunteers is not too onerous and there us a perceptible end product in the shape of a conference.
- \* The system works as close to the public as you can get: in their homes, coffee/tea shops, pubs and work places. The meetings take place in these locations.



## CLUSTER GROUPS HOW ARE THEY ORGANISED?

- Co-ordinated by the CHC
- The groups meet in informal settings (pubs, coffee shops, friends' houses)
- They meet four times a year + specials
- Travel and Carers costs are paid
- CHC staff write a report of each meeting which is circulated to the HA and SS

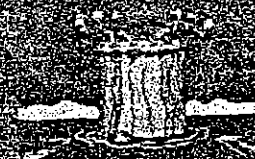
Mellor CHC

22/06/96

7

## CLUSTER GROUPS SHOULD THEY CONTINUE?

- The Health Authority has agreed to support the CHC with funding to continue for another year
- Members are enthusiastic and want to stay on the cluster groups



Mellor CHC

22/06/96

8

## CLUSTER GROUPS A REVIEW OF THE FIRST YEAR

Question Time has been organised to highlight the questions raised and give the managers a chance to respond.

Mellor CHC

22/06/96

9

## PERFORMANCE STANDARDS THROUGH CHARTERMARK

Session Leaders: Gordon Tollefson and Louise Bentley,  
Pontefract CHC

Rapporteur: Dave Lee, Islington CHC

### FORMAT OF THE SESSION

- a) To look at specific Charter Mark Standards
- b) To look at examples of how these can be adapted to the work of the CHC
- c) An Open Forum to consider some essentials in any standards for CHCs

### What is Charter Mark?

Charter Mark is the Prime Minister's Award for the quality of service provided to the public. While Pontefract is not a 'Prime Minister supporting CHC', it was decided to de-politicise the matter. The process was seen as an opportunity to look at CHC services against specific criteria. It was felt that if the Benefits Agency, Passport Office etc could deliver a certain level of service, the CHC can also gain from a comprehensive and independent validation of what is going on.

A Charter Mark means an organisation has shown that it puts its users first.

The Charter Mark is not just an award scheme. The nine criteria are helpful for measuring the service your organisation provides, whether or not you decide to go on and apply.

### Why should CHCs have standards?

- a) CHCs monitor other Organisations' performance against their standards
- b) Standards can give direction
- c) They can be rewarding and satisfying

### CRITERION 1

#### Standards

"Setting, monitoring and publication of explicit standards for the services that individual users can reasonably expect. Publication of actual performance against those standards."

#### Evidence for Criterion 1

Standards included answering the phone within 3 rings and keeping the office tidy, eg, putting leaflets where they should be. Regular contacts, such as Trusts, were asked to call to check if the '3 rings' standard was being met.

Standards were developed in consultation with members and the public.

Performance was published in quarterly reports to CHC meetings, the bi-monthly newsletter and the annual report.

**CRITERION 2****Information and openness**

"Full, accurate information readily available in plain language about how public services are run, what they cost, how well they perform and who is in charge."

**Evidence for Criterion 2**

- In-house literature developed for:
  - general public
  - schools
  - hospitals
  - GPs and the PHCT
- Information Service provided by the Health Information Centre
- Occasional Booklets

**CRITERION 3****Consultation and choice**

"The public sector should provide choice wherever practicable. There should be regular and systematic consultation with those who use services. Users' views about services, and their priorities for improving them, are to be taken into account in final decisions about standards."

**Evidence for Criterion 3**

**Methods used:**

- Focus groups
- Coffee mornings
- Mobile Presentation Unit
- Evening talks
- Patient satisfaction study
- Complaints questionnaire
- Office questionnaire
- Suggestion box
- CHC Newsletter
- Self assessment forms

**CRITERION 4****Courtesy and helpfulness**

"Courteous and helpful service, from public servants who will normally wear name badges. Services available equally to all who are entitled to them and run to suit their convenience."

## Evidence for Criterion 4

- Name badges worn at all times
- Customer service training
- Standards monitored by external agencies
- Photographs and names of staff displayed in reception
- Converted premises with purpose built ramp
- Rooms available for private interviews
- Home visits
- 'One-stop shop'

**CRITERION 5**

## Putting things right

"If things go wrong, an apology, a full explanation and a swift and effective remedy. Well publicised and easy-to-use complaints procedures with independent reviews wherever possible."

## Evidence for Criterion 5

- Complaints procedure issued by ACHCEW
- Leaflet - 'How to make a complaint about the service we provide'
- Advertised in our Charter
- Review of enquiry record forms at the monthly staff meeting
- Complaints book

**CRITERION 6**

## Value for money

"Efficient and economical delivery of public services within resources the nation can afford. And independent validation of performance against standards."

## Evidence for Criterion 6

- Collaboration with the Health Authority
- Budget comparison over the years related to the number of users of the CHC
- E-Mail
- In-house production of literature including the annual report
- CHC finances audited internally and externally

**NB** - Tremendous value of members' voluntary contributions.

**CRITERION 7**

## User satisfaction

"Evidence that users are satisfied with the service you provide."

## Evidence for Criterion 7

- Complaints questionnaire
- Satisfaction survey completed by visitors to the Health Information Centre
- Evaluation forms
- Focus group feedback
- Snapshot surveys



**CRITERION 8****Improvements in the quality of service**

"Measurable and demonstrable improvements in quality of service over the last two years."

**Evidence for Criterion 8**

- Move to new premises
- Complaints database
- Home visits
- Improved technology
- Health Promotion Resources

**CRITERION 9****Innovative enhancement**

"To have in hand or plan to introduce at least one innovative enhancement to services without extra cost to the taxpayer."

**Evidence for Criterion 9**

- Setting up self-help groups
- CPR
- GP Project

**OVERVIEW**

- You are setting yourself tough standards
- You are telling users what those standards are and whether you are achieving them
- You are telling users about all the services and help available
- You are asking users what services they need and how they think you can improve your services
- You are making good use of users' ideas
- You are giving users a choice whenever possible
- You have polite and helpful staff who go out of their way to meet users' needs
- You are making it easy for users to say when they are unhappy
- You are acting quickly to put problems right
- You are giving value for money and spend public money carefully
- You have improved the quality of your service and you have new ideas for more improvements in the future
- Your users agree that you are providing a really good service

The Information Centre has developed as a result of a contractual agreement with the health authority, without any loss of the CHC's independence. The merged HA HQ was in Wakefield, so the case for information services in Pontefract was strongly made.

In 1992 there was one personal caller and 42 phone calls to the office. In 1994 there were 1553 personal inquiries and 652 phone enquiries.

The HA had been keen to put in a joint charter mark bid in 1993, but there was no evidence to back it up, so it didn't get past the starting gate. It was decided to put in a CHC bid, working towards June 1994 with a view to submitting a comprehensive bid in 1995.

In terms of organisational benefits, members new feel more confident in saying 'This is the service you'll get from the CHC.' All staff feel that they have achieved something and constantly want to do things better. Staff have been pulled together as a team with a system in place in which everyone knows what they are meant to be doing.

Members who could help were enlisted, acting as monitors of the service. They were involved with staff in going through the bid and commenting. They have also helped in covering the office, going out to speak to groups and assisting on roadshows.

The CHC covers a population of 178,000 and there are 6.8 whole time equivalent staff. 3.2 are 'core funded' but there is no differentiation between the work done from HA funding. A lot of health promotion work is done - eg, a blood pressure testing day attracting 175 people - and through this the CHC is promoted.

The office has occasionally opened on bank holidays when there is an event in the area. Weekend opening could jeopardise the achievement of standards Monday to Friday.

About 6 events a year are covered at weekends, eg, open days at hospitals, and it is planned to increase this next year.

Standards include the provision of training to members, though not on visiting.

One method of obtaining feedback has been to arrange an open evening/buffet with officers of local voluntary organisations to discuss what they want from the CHC.

Support in developing the bid was obtained from local organisations who had already attained Charter Mark. The bid is 9 pages of A4: 1 page for each criterion. With appendices the bid ended up as a ring binder. 2 seminars were arranged for bodies submitting bids, though these tended to focus on larger organisations.

BS5750 can be very expensive to bid for, but a Chartermark bid has no direct cost.

The CHC's accounts are subject to internal audit from the HA and external audit every three years, arranged through Region.

The CHC has helped establish a number of Self Help Groups including a Mental Health Users' Group and a cancer group.

The CHC has a formal equal opportunities policy which is publicised.

Members who answer the phone are trained and briefed. Confidentiality is maintained as they only take an outline to prevent clients having to go over the same story twice. They explain that staff are busy (eg, during staff meetings).

On the question of paperwork, there is not multiple casework per client. One particular member of staff is responsible for certain data on certain areas. Staff become used to it and it is now second nature.

There was some concern expressed about the political context of the Chartermark, and the feeling that it failed to recognise the issues of resources in the public sector. There is also the question of whether the time spent filling in monitoring forms could be better spent providing services directly to the public. However Pontefract CHC staff said they felt they had gained a lot from preparing the documentation.

Copies of the Chartermark bid are available from Pontefract & District CHC

## **BREASTFEEDING - GOOD PRACTICE GUIDANCE TO THE NHS**

**Cynthia Rickitt, National Breastfeeding Co-ordinator**  
**Rapporteur: Lesley Stirling-Baxter, Bradford CHC**

Breastfeeding is not seen as 'normal' by our society. Nonetheless 64% start to feed at birth, but 12% have given up by the time they leave hospital.

20% give up after two weeks - only 40% continue to breastfeed for six weeks.

The figures come from OPCS samples and Cynthia believes that the data might be inaccurate - more people may be breastfeeding.

Why is breastfeeding so good? It gives babies the best start in life. It reduces the risk of developing :-

- Gastro-enteritis
- Infections of middle ear, respiratory tract system and urinary tract
- Insulin-dependant diabetes
- Allergies such as eczema

*Pre-term babies neurological systems grow better with breast-feeding.*

The risk of necrotising-enterocolitis is reduced. (All of this has been proved by research.)

There are also benefits to the mother:

- Reduced risk of pre-menopausal breast cancer
- Reduced risk of some forms of ovarian cancer
- Stronger bones in later life
- Ready availability for baby
- Empowerment
- Natural weight loss after birth
- Unique contact between mother and baby

**Breastfeeding good practice guidance:**

This reflects the government's commitment to:

- WHO International Code of Marketing Breastmilk Substitutes
- UNICEF and the UN Convention on the rights of the child
- Report of the Parliamentary Select Committee on Health

The guidance is to raise awareness of the importance of breastfeeding.

CHC members can use their position to help in the development of local breastfeeding standards.

## **MATERNITY SERVICES LIAISON COMMITTEE**

The function of these committees was explained as some CHC members present were unaware of their existence or purpose. These committees provide an opportunity to ensure maternity services locally meet woman's needs.

## **BREASTFEEDING OPERATIONAL TARGETS (Innocenti declaration)**

All governments by the year 1995 should have:

- Appointed a national breastfeeding committee and co-ordinator
- Developed national goals and targets for action

The unique benefits of breastfeeding were recognised. A national network of breastfeeding co-ordinators has been established. Their terms of reference are to promote and protect breastfeeding by:

- Stimulating and sustaining action at local level
- Sharing ideas nationally

With the aim of increasing both the number of mothers who breastfeed and the length of time they continue to breastfeed.

CHCs were asked to find out who their local co-ordinator for breastfeeding is and what their links are with Regional co-ordinators. (It appears some areas have not bothered to designate an individual despite instruction from the Department of Health.)

Breastfeeding targets should appear in local contract specifications and strategic directions.

## **GENERAL COMMENTS**

GPs are often not aware of the rules regarding the advertising of alternatives to breast feeding.

## **COST SAVINGS TO THE NHS**

The rate of admission to hospital for a bottle fed baby is five times higher than that of a breastfed baby at a usual cost of £1,200 an incident (gastro-enteritis). This works out at £400,000 per district.

## **PURCHASERS**

Purchasers should have published policies on breastfeeding, which are communicated to mothers. Breastfeeding strategies should be audited to see how successful they are.

## **TEN STEPS TO SUCCESSFUL BREASTFEEDING (UNICEF)**

These can be used when looking at local quality standards and successfully adopted.

CHC members should ask when visiting maternity units:

Managers:-

- when was your breastfeeding policy last reviewed?
- is training on breastfeeding given to staff in your unit?
- what facilities are there for women to express breast milk?

Names and contact numbers of Breastfeeding co-ordinators:

- **TRENT** - Lindsay Cullen - Tel: 0115 924 9924 ext. 44867
- **NORTHERN & YORKSHIRE** - Liz Moloney - Tel: 0191 454 8888
- **SOUTH THAMES** - Gill Rapley - Tel: 01795 478175
- **SOUTH & WEST** - Penelope Samuel - Tel: 01202 704684  
Mandy Curry - Tel: 0117 957 3206
- **ANGLIA & OXFORD** - Rosamund Miller - Tel: 01865 221722
- **NORTH WEST** - Christine Clark - Tel: 01524 583874
- **NORTH THAMES** - Kanta Patel - Tel: 0181 552 2381
- **WEST MIDLANDS** - Brenda Bartlett - Tel: 0121 472 1377 ext. 4284

## REPRESENTING THE PUBLIC?

Session Leaders: Alan Burnside, North Tees CHC and Denis O'Driscoll,  
Calderdale CHC

Rapporteur: John Godward, Airedale CHC

The title should be '*Representing the Public through research*'

Research has an impact upon our lives - more so now than before.

Why should we do research? = To test a hypothesis - Asking and Finding Out - It gives us a greater understanding of what people think.

Types of Research	Action Research
	Case Study
	Ethnography
	Surveys

**ACTION RESEARCH** - Supposing you find out from psychiatric patients that there is no counselling service. One is then set up. The research can continue with the question, - 'Is the service adequate?'

**CASE STUDY** - talk to carers, patients - may not be appropriate for the next case. Case study is valuable for one set of circumstances.

**ETHNOGRAPHY** - controversial - pretend to be a member of a group. Raises ethical issues, but is an extremely valuable form of research because the experience gained is personally experienced.

**SURVEYS** - statistics are facts. The suspicion comes in, however, when the interpretation is made. Care has to be taken when setting question(s). Surveys can ask How, When, Where, but not Why.

It is a requirement of CHCs. to represent the public - the whole public. They do this through -

- (1) Complaints
- (2) CHC Members raising issues or concerns
- (3) Formal and informal visiting
- (4) NHS members of staff voicing their concerns
- (5) The medical highlight problem

### The CHC benefits by employing a Researcher

- (1) CHC generates its own independent data
- (2) The CHC can better represent its local people and its credibility is enhanced
- (3) Members gain invaluable skills and become more confident
- (4) Research activities become co-ordinated and structured and, therefore, have a greater impact

### Problems with short term contracts for Researchers -

- (1) Lack of continuity
- (2) The research agenda is not by someone else
- (3) Good links with people in the community are lost
- (4) Community based issues constantly change - nothing stays the same
- (5) It is difficult to follow through recommendations

The reactive CHC is waiting to hear of things happening, when CHCs. should be discovering what is happening, through research.

CHCs. should have someone properly trained to undertake research, rather than believing that amateurs, in the form of Members, can do this work with efficiency and effectiveness. This is not to diminish the sterling efforts of voluntary members of CHCs., but professionalism does count with Health Authorities and Trusts.

The Workshop provided a practical exercise, with participants having to think up the questions which they would ask patients on a Ward.

**JOHN D. GODWARD**  
 Chief Officer of Airedale CHC.  
 12th July 1996

## GP FUNDHOLDING: THE BENEFITS

**Session Leader: Dr David Tod, Immediate Past President, National Association of Fundholding Practices**  
**Rapporteur: Heather Rutt, North West Herts CHC**

Dr. Todd gave a brief account of the history of GP Fundholding. His Practice had been one of the first wave of 290 Fundholders and had been allocated £1.5 million for staff, drugs, hospital referrals for out-patients and some elective procedures. They had to demonstrate that they were computerised and could track patients and send invoices. Dr. Todd said they learnt as they went along; one hospital had had no knowledge of Fundholding for the first 6 months and simply dropped invoices in the dustbin. There were currently 3,500 Fundholders who covered 50% of the population.

Changes had taken place since GP Fundholding started. They had tightened up accountancy systems, had to produce firm business plans and now agreed how contracts were enforced with Providers. For instance one large hospital only undertook Day Surgery for 15% of patients; when faced with the threat that patients would be sent elsewhere, the hospital agreed to undertake Day Surgery for 50% of patients.

Dr. Todd referred to the Audit Commission Report and said that this had been interpreted in various ways. His talk concentrated on the benefits shown in the best GP Fundholding Practices.

### **Benefits:**

#### **1. Practice-Based:**

Teamwork was encouraged with more regular meetings which included District Nurses and Midwives and other staff. New services had been started such as counselling for the bereaved, well-men clinics and nurses had been given additional training in family planning, in taking cervical smears and in asthma care.

Dr. Todd said that 84% of the Fundholders had introduced new services; there were 31 different types of service introduced ranging from physiotherapy to acupuncture. His own practice had started a monthly Consultant Clinic in the GP surgery for orthopaedics and another for dermatology. They had managed to negotiate a dedicated slot in a hospital outpatient clinic for their patients with a guarantee that the patient would see the consultant. Preliminary work within the GP surgery had meant that the initial spadework prior to an operation had been done which was more efficient. Dr. Todd said that not all Fundholders were efficient; 10% were not better as a result of becoming Fundholders.

#### **2. Patient Consultation:**

Dr. Todd gave examples of how contracts had been switched from large to smaller hospitals which were able to give a guarantee to see patients quickly and offer operations within 3 months. Patients were asked if they were prepared to travel 10 miles away rather than 7 miles in order to get their operation done more quickly. 95% of patients were happy to go to the more distant hospital. This arrangement was for orthopaedics and similar arrangements were made for ophthalmology.

Although individual patients were given choice and consulted, Dr. Todd said that Patient Participation Groups had not worked. This was possibly because of the very mixed population where 5 different languages were spoken. They informed the local CHC of their work but had no formal consultation; the practice bordered on 3 different CHC areas. Dr. Todd mentioned that many colleagues were totally opposed to CHCs although some Health Authorities got on well with CHCs.

#### **3. Managing Waiting Lists:**

Dr. Todd said that GPs were in a better position than distant consultants to make decisions about which patients should have priority on the waiting list. Consultants liked GPs to take this responsibility for them. Private hospitals could be used to clear waiting lists. Dr. Todd gave an example of £10,000 being offered to a private hospital to treat 20 patients on the waiting list; this was offered to the patients and 18 agreed to this although 2 didn't want to use a private hospital. Physiotherapy was



another example of a service which could be provided more cheaply in the private sector with more choice of time of appointments for the patient.

A benefit was the improvement in the concept of *total patient care*. Previously a patient might be referred to hospital and have 3 operations without information being fed-back to the referring GP - 20% of letters used to go astray whereas now the error rate was 5%.

#### **4. Evidence-based Care:**

Looking at costs encouraged doctors to look at the outcomes of treatment. Patients with acute back pain appeared to be better if treated by physiotherapists rather than going to hospital to have an operation.

#### **5. Audit of Service:**

The audit of contracts which compared costs and service-provision were good and benefited non-Fundholders.

#### **6. Hospital and Community-Based Services:**

Fundholding had improved waiting times; it meant that GPs followed-up patients rather than Junior Doctors. It had also showed where there were needs for increased services; for instance, a *dermatologist and neurologist might be required instead of an additional cardiologist*. Research undertaken by Clive Parr, FHSA Director, had shown that patients wanted better standard treatment rather than more heart or kidney transplants.

The rise in emergency admissions had not been influenced by GP Fundholding. This was more a problem for Accident & Emergency Departments where Junior Doctors admitted more patients than Consultants. Hospitals tended to say there were not sufficient patients to justify 24-hour Consultant cover although this would limit the number of admissions.

Community care had improved with more Social Workers, CPNs coming into the surgery than used to be the case.

#### **7. Health Authority Benefits:**

The Health Authority had come to the doctors to talk about its Strategy and there was better joint development. Dr. Todd's practice had given £100,000 towards funding a *Stroke Unit* which would benefit everyone. Fundholders met together to share ideas. They also worked with Public Health Consultants in assessing morbidity and mortality statistics in various specialist units. They had been able to get statistics for their own practice population.

#### **8. National Benefits:**

The advent of Fundholding had stimulated thinking on primary care and had acted as a catalyst for change in attitudes of the *Purchasing Authorities and Trusts*. Although Dr. Todd acknowledged that some doctors hadn't changed firmly-held ideas, GP Fundholding had stimulated a culture change. In London and other large conurbations GPs and Consultants still tended not to know each other and *didn't communicate*.

#### **9. Financial Benefits:**

75 % of Fundholders had made savings and 10% had made losses. The savings had been spent on equipment, premises, staff and on new Community and Trust services. Overall the Fundholders had stimulated Trusts and Health Authorities to make savings.

The Audit Commission Report said that £230 million had been saved and £206 million had been lost. Dr. Todd posed the question: *"Is it worth it?"*

Dr. Todd had given an enthusiastic account of his own Fundholding experience. He added, in response to questions, that the Kings Fund was undertaking a 3-year assessment. The National Association of Fundholding Practices was looking to build a framework for strategic planning with ACHCEW.

## TRAINING FOR DELEGATED HEALTH CARE TASKS IN THE COMMUNITY - WHOSE RESPONSIBILITY IS IT?

**Session Leaders: Anne Godfrey and Pauline Hart, Crossroads Caring for Carers**

**Rapporteur: Barbara Wilson, Pembrokeshire CHC**

Anne Godfrey commenced her presentation by explaining that in 1973 it was recognised that carers of children, adults and older people who have either physical disabilities, learning difficulties, mental health problems, a chronic illness or palliative care needs require both practical support and domiciliary based respite care. Since that date 300 care attendant schemes have been established throughout England, Scotland and Wales.

The structure of each scheme is very similar, having a Voluntary Management Committee and employing a Co-ordinator/Scheme Manager, a Deputy Co-ordinator, Care Attendants and Clerical Assistant. Joint finance and grant aid historically funded such schemes but Community Care has led to service diversification, contracting and other funding opportunities.

Whilst striving to maintain a high standard of care their objective is to supplement and complement, not to replace, existing statutory services. The aim being "to relieve stresses experienced by carers and people with physical, mental or sensory impairment within the family or home, by offering a respite service through the provision of community based care attendants." Whilst providing a quality service they strive to be flexible, reliable and consistent; to perform the wide range of tasks normally carried out by the carer which can include basic nursing care as well as personal care, essential light domestic duties in addition to social care and leisure activities.

Families may not appreciate that in taking on responsibility for certain specialised tasks because of cuts in community nursing and earlier hospital discharges, they could be tied with little support to the person being cared for 365 days of the year. Social Service departments will not take on nursing tasks. In recent years carers have been expected to take on delegated health care. In order to protect users of services and staff, Health Trusts have been asked to provide appropriate training, not all are prepared to do so. The alternative is for Community Nurses to continue specific tasks whilst Carers provide basic care. (Appendix I)

Crossroads are insured for medical malpractice as are over 50% of Health Trusts by St Pauls Insurance, their personal care and medicine policy recognises that staff are able to develop a range of specialised skills (Appendix II) with appropriate training. The Royal College of Nursing acknowledges that it is the responsibility of Health Trusts to provide training where agencies have taken on delegated health care tasks, Crossroads asked for the support of CHCs in their negotiations with the Department of Health in respect of this issue.

The detailed and interesting presentation raised various questions about training and monitoring of staff as the session progressed:

- We learnt that some further education centres now offer appropriate training and that Carers themselves feel valued if they obtain NVQs;
- Monthly meetings are held with the Co-ordinator to pick up problems that staff might be experiencing;
- Questionnaires are supplied for families to complete after six weeks and six months;
- There is a full case review after twelve months whereas Health Authorities frequently do not revisit the package of care they purchase;
- The lack of accountability within community care concerned representatives at this session, it was considered that domiciliary care for the most vulnerable in our in the community had potential for abuse;
- Schemes work closely with the Alzheimers Disease Society, Community Psychiatric Nurses and Community Nurses;
- Pressure is increasing in some areas for Crossroads to provide the whole service rather than supplement what is in place, yet limitations have been imposed by their Risk Managers in St Pauls Insurance and there is now a list of Prohibited Tasks (Appendix III) some of which Carers had traditionally performed.

IN THE UK TODAY THERE ARE OVER 3 MILLION MEN AND 4 MILLION WOMEN CARING FOR THEIR RELATIVES:

- 78% of people in employment have no direct experience of caring
- 84% of people in employment do not expect to have to give up work to care
- 18% of carers at work had taken time off in the last month to care
- two thirds of carers in the workforce are women
- only 12% of carers had received help from health and social services
- only 22% had taken out insurance policies to cover long term illness for their families and themselves.

The Association of Crossroads employs 2,900 Care Attendants providing over 2 million hours of care to over 25,000 families.

## BASIC TASKS

ALL care attendants must be able to undertake these tasks competently, following Induction:

- 1... Bathing in bed/bathroom/chair to include aspects of personal hygiene.
- 2 Assistance with management of continence of bladder and bowel.
- 3 Assistance with dressing and undressing.
- 4 Assistance with mobility and transfers.
- 5 Assistance with feeding.
- 6 Administer medication as prescribed by Medical Practitioner and in accordance with Crossroads Medicines Policy.
- 7 Assistance with therapeutic programmes for rehabilitation and development as agreed with visiting clinical professionals.
- 8 Ensuring a safe environment in accordance with Crossroads Health & Safety Policy.
- 9 Supporting the person with a disability outside their home.
- 10 Assistance with getting up and going to bed.
- 11 Assistance with appliances (hearing aids, spectacles, artificial limbs, leg callipers etc)
- 12 Care of skin and hair, including assistance with shaving.
- 13 Care of pressure areas and prevention of sores.
- 14 Care of mouth and teeth, including dentures.
- 15 Summoning emergency services if necessary.

## SPECIALISED TASKS

Care attendants may be asked to undertake these tasks at the discretion of the co-ordinator/manager AND AFTER TRAINING as specified. Care attendants should only agree to undertake these tasks if they feel capable and competent to do so. All such training MUST be recorded with the date, content and qualification of the trainer. A record should be kept of all specialised tasks undertaken.

1. Administering prescribed medication orally.
  - Training by Community Pharmacist.
2. Administering prescribed medication via a naso-gastric tube.
  - Training by the nurse with responsibility for the patient.
3. Injections (intramuscular or subcutaneous) with a pre-assembled pre-dose loaded syringe.  
 The care attendant must check the medication together with the person with care needs/carer and observe it being drawn up for administration.
  - Training by the nurse responsible for the patient or the diabetic liaison nurse or district nurse.
4. Assistance with eye drops and ear drops
  - Training by GP or District Nurse
  - Understand the potential effects and possible side-effects and know who to contact in an emergency.
5. Inserting suppositories or pessaries
  - Training from the nurse with responsibility for the patient.
6. Emergency Treatments  
 Rectal medication
  - Training by individual's GP, Community Nurse or Paediatric Nurse, with written guidance in relation to the individual. Training must include advice on the circumstances in which care attendants should act and pointers to look for. When recording action taken, care attendants should note symptoms/signals which prompted their intervention, as well as medication given.
7. Assistance with inhalers, insufflation cartridges and nebulisers
  - Training by the nurse responsible for the patient.
  - Written guidance on number of inhalations and what to do if no effect.

8. Monitoring of metered dosage device (eg. Syringe-Drivers) and of additional bolus doses (pressing the button to administer the dosage).
  - Training by GP or District Nurse with responsibility for the patient.
  - Understand how it works and why; signs of incorrect working and know who to contact in an emergency.
9. Assistance with oxygen administration
  - Training by GP or District Nurse.
  - Understand signs/symptoms requiring oxygen administration, rate of flow, % mask, litres per minute, signs/symptoms of overdose, how to change a cylinder, safety precautions re storage and use of oxygen cylinders, recording systems as required.
10. Administering controlled drugs orally (see section 7).
  - Training by a GP or named nurse responsible for the patient or pharmacist.
  - Care attendants must be fully aware of contra indications, possible side effects and subsequent action to be taken.

## PROHIBITED TASKS

- 1 Toe-nail cutting or filing.
  - 2 Ear syringing.
  - 3 Removing or replacing urinary catheters.
  - 4 Bowel evacuation (other than suppositories).
  - 5 Bladder washouts.
  - ✱ 6 Injections - involving assembling syringes  
- administering intravenously  
- controlled drugs.
  - 7 Lifting individual from the floor unaided.
  - 8 Tracheostomy Care - changing of tubes.
  - 9 Haemodialysis.
- ✱ See also - Crossroads Medicine Policy.