King's Fund

Primary Care

Themes from a series of workshops held at the King's Fund in the Summer–Autumn of 1996

Ros Levenson

Primary Care

Themes from a series of workshops held at the King's Fund in the Summer–Autumn of 1996

Ros Levenson
Independent Policy and Training Consultant
and Visiting Fellow, King's Fund Development Centre

Published by
King's Fund
11–13 Cavendish Square
London W1M 0AN

ISBN 1 85717 145 4

A CIP catalogue record for this book is available from the British Library.

Further copies of this report can be obtained from the King's Fund bookshop.
Telephone 0171 307 2591

Contents

Introduction

In the summer and autumn of 1996, with the financial support of the former North Thames Regional Health Authority, the King's Fund organised and hosted a series of workshops for managers and practitioners on various aspects of primary care. The workshops were as follows:

14 June 1996	What makes change happen in primary care?
6 September 1996	Primary care and frail elderly people
9 September 1996	Mental health and primary care
21 October 1996	Primary care and vulnerable adolescents
25 October 1996	Primary care at 3am – emergency and out-of-hours care

The June workshop set the context for discussion, drawing on a series of books on primary care from the King's Fund, published by Radcliffe Medical Press. The autumn workshops focused on specific aspects of primary care. Each workshop consisted of presentations from eminent speakers who were active in their field as academics, managers or practitioners and was followed by small group discussion sessions on particular issues and topics.

Some of the material was mainly pertinent to the specific topic under discussion, but a surprising number of common issues were identified across the board.

This brief report presents some of the main themes that emerged from the workshops, and seeks to make links, where appropriate, between them. In some instances, quite large excerpts from presentations have been included. In other places, the overall flavour of the discussion has been given, sometimes ranging across the presentations of several speakers, as well as the contributions of the participants of the series of workshops. In the interests of brevity, and because themes tended to recur across the workshops, no attempt has been made to give a comprehensive report of all the presentations, since it is the common themes and the transferable learning that are most important, both for those who attended the conferences and for others. Themes have been grouped under broad headings to enable readers to refer to those sections that are of particular interest to them.

Omissions of particular presentations are in no way a reflection on the interest or merit of the individual contributions made by speakers, all of which were immensely valuable. It is simply that this report aims to present themes from the workshops, illustrated by presentations where that is particularly helpful. The programmes for the workshops appear in the Appendix.

Acknowledgements

The following people gave talks, chaired conferences or led workshops:

Dr Sheila Adam
Helen Allen
Christine Beasley
Elaine Best
Dr Kathie Binysh
Laurie Caple
Judi Clements
Dr Alan Cohen
Dr John Coleman
Helen Fentimen
Martin Fischer
Caroline Glendinning
Dr Michael Gocman
Lesley Hallam
Judy Hargadon
Jo Hesketh
June Huntington
Dr Chris Jephcott
Paula Jones
Dr Zarrina Kurtz
Val Lattimer
Judi Linney
Barbara McIntosh
Dr Ann McPherson
Geoff Meads
Huw Meredith
Dr Jackie Morris
Alison Norman
Eileen O'Keefe
Dr Diane Plamping
Dr Mark Reynolds
Michele Sappa
Hilary Scott
Dr Rod Smith
David Tait
Dr Stephen Miles
Dr Tim Van Zwanenberg
Julie Webb
Debbie Williams
Susan Williams
Judie Yung

The King's Fund acknowledges the support of the former North Thames RHA for their contribution to making these workshops possible.

Chapter 1

The changing context of primary care

Population changes and changing patterns of need

The health needs of a population change over time and may alter as the population itself changes. Life expectancy and, in particular, a lengthier period in which health care may become all the more necessary are important factors. While such factors may affect the whole spectrum of health care, the need for primary care is likely to become increasingly to the fore.

All the workshops in the series put the need for primary care in the context of changes in population, and many speakers gave information on demographic factors and on patterns of illness and treatment.

YOUNG PEOPLE

Young people/adolescents make up about 12% of the population. This has fallen from 16% in the 1980s. Overall, psycho-social disorders affect at least 20% of young people.

For the 10–19 age group, about 50% of deaths are the results of accidents, and 16% are from cancers. Overall, young people are a healthy age group, but they do use health services, and for similar reasons as older people. Looking at inpatient episodes, for girls aged 10–19, the commonest reason for hospital admission is pregnancy-related, while for boys the commonest reason is trauma. Young people visit GP surgeries for respiratory complaints, infectious diseases, skin problems and injury.

The lifestyle and behaviour of young people

There are a number of high-risk behaviours that occur more commonly in young adults:

- lower age at first intercourse and/or more sexual partners
- smoking
- excessive alcohol intake and alcohol-related road accidents
- sharing injecting equipment
- accidents
- low consumption of fresh vegetables and fruit
- sunburn.

Suicide also occurs more commonly in young adults.

cont.

Sexual behaviour

There is a Health of the Nation target for reducing conception rates in young adolescents by 50% from the 1989 rate. The rate was rising to 1990, then falling to 1994, but there was a small rise in 1994. The 16–24 age group has the highest numbers of people having had two or more heterosexual partners within the previous year, and there are messages about sexually transmitted diseases and HIV/AIDS to get across to this age group.

Smoking

The Health of the Nation target for reducing cigarette smoking in the 11–15 age group, to less than 6% by 1994 has not been met. There is a worrying number of young women taking up smoking. Also, a significant minority of about 2% are smoking by age 11. By the age of 15, rates resemble those for the general population.

Mental health

8% of 7 year olds and 1% of 14 year olds suffer from nocturnal enuresis. Major depression affects 2–8% in adolescents. 2%–4% of adolescents attempt suicide. The suicide rate is 7.6 per 100,000 among 15–19 year olds.

Drugs

The 1992 British Crime Survey reports that 3% of 12–13 year olds and 14% of 14–15 year olds say they have ever taken an illegal drug. The Health Education Authority states that in 1992, 3%-5% of 11–16 year olds and 17% of 17–19 year olds say they have used cannabis.

Accidents

Young people, particularly young men, have a high rate of accidents. For males aged 16–24, 10% have had an accident – often a road accident in which they were the driver – in the previous three months.

Physical activity

There is a big sex difference for participation in vigorous physical activity, and a big fall-off with age. Some 25% of males aged 16–24 are regular participants.

Diet

Young people use slightly less saturated fat, and a little more soft margarine than older people.

Source: Dr Kathie Binysh, Senior Medical Officer at the Department of Health

CHILDREN GROWING UP WITH CHRONIC ILLNESS

Chronic illnesses in children may include:

- Diabetes
- Cystic fibrosis
- Epilepsy
- Sickle cell anaemia
- Cerebral palsy
- Cancer
- Congenital heart disease
- Asthma
- Rare conditions, such as brittle bone disease, Tay Sachs, etc.

Some conditions sometimes occur together (e.g. cerebral palsy and epilepsy.) Some are associated with varying degrees of learning disability (e.g. cerebral palsy). There may be overlapping but also somewhat different issues for conditions such as Down's Syndrome, where the primary problem is learning disability. This is because the appropriate specialist services have a greater focus on education rather than health, although general medical care remains important.

The care of young people growing up with chronic illness is virtually a new field, for two reasons:

- adolescence is newly defined as a stage of life which, in terms of needs for health care, sits between paediatrics and adult medicine and has its own particular features;
- there have been enormous changes in the incidence, prevalence and natural history of a number of medical conditions.

Many children who would have died in previous generations now live into adulthood. For people with conditions such as cystic fibrosis there remains a significant risk of dying in early adulthood. For a great many others, major developments in management and technologies mean that the risks of serious and disabling consequences of their illnesses are much reduced.

The OPCS survey of disability in Britain found disabilities likely to have a significant effect in carrying out normal everyday activity in 3.5% of 10–15 year olds; nearly two- thirds of these children had more than one disability, the greatest majority being in the area of emotional and behavioural disorders.

The overall prevalence of chronic illness in the adolescent population has not been studied, although proxy measures such as the need for special educational provision, as in the Warnock Report, suggest that it is about 20% of school-age children.

Information from special studies about individual conditions suggest how often a primary care practice can expect to meet a young person with a particular condition. The role of primary care will be influenced by how commonly a particular condition presents.

cont.

For example:

- Cystic fibrosis is now the most commonly inherited condition in Caucasians in this country, with a birth prevalence of about 1 in 2000.
- Sickle cell disease predominates among West Africans and African Caribbeans, who form more than 2% of the population.
- The current birth prevalence of cerebral palsy is of the order of 2 per 1000.
- Epilepsy has a number of different causes and may present at any age, but has a prevalence of nearly 5 per 1000 in 16 year olds.
- Insulin-dependent diabetes has grown in incidence in under 16s, and has nearly doubled in the past decade from 7.9 to 13.5 per 100,000.
- The prevalence overall of chronic illness in young people is growing, partly because some conditions such as diabetes are actually on the increase, and partly because in almost all these conditions, survival has greatly improved.

Source: Dr Zarrina Kurtz, Consultant in Public Health and Health Policy

FRAIL ELDERLY PEOPLE

Key facts and figures include:

- the population of over-65s will be 6 times greater in 2001 than it was in 1901
- the population of over-85s will be 25 times greater in 2001 than it was in 1901
- life expectancy has risen over the past 100 years and continues to do so; in the last 10 years, life expectancy for women has risen by a year. Life expectancy is now 78.5 years for women, and 72.9 years for men.
- UK figures are not as good as Southern Europe.

A key question is: are we prolonging a period of terminal disability, or can we have a longer life with a shorter period of terminal disability?

Source: Dr Jackie Morris, Consultant in Medicine of Old Age, Royal Free Hampstead NHS Trust

MENTAL HEALTH

- The primary care team manages most mental health problems, with specialist services meeting the more complex needs
- Mental health problems are very common, with 1 in 7 people reporting significant anxiety and/or depression during the preceding 2 week period
- 1 in 3 GP consultations have a mental health component.

Source: Dr Sheila Adam, Head of Mental Health and NHS Community Care, Department of Health

The underlying message at all the workshops was that primary care needs to keep up with and anticipate demographic and epidemiological factors. Population changes, the range of available treatments and the growth in the numbers of people who need treatment and support in the community for long periods of time all pose major challenges to primary care development.

Rising demand and expectations

While need and demand are linked, a recurring theme across the workshops was that in addition to changing population structure and epidemiology, there had been significant changes in expectations from users and potential users of services. At times, it seemed as though primary health care professionals felt that they were under a state of siege, with demand forever outstripping the capacity to meet it. There was considerable debate on whether rising demand was appropriate or inappropriate.

On the whole, the prevailing view was that patients usually only requested a service when they actually needed it. Indeed, for some groups, such as older people, there was thought to be a reluctance to use services, rather than an inappropriate over-use of services. While patients might sometimes need information on what service was best able to respond to their needs, or information to assist them in deciding what help they needed, most people accepted that if patients perceived that they had a need for help, then that was reason enough to take them seriously. It was reassuring that the debate seemed to have moved on from the (recent) era in which rising demand was all too frequently equated with inappropriate demand.

Most speakers and participants seemingly accepted that rising demand was an inevitability, and that to some extent, it reflected an increasingly consumerist society. As one participant commented, 'We have 24 hour banking and shopping, so naturally people expect 24-hour primary care'.

The main concerns about rising demand surfaced at the workshop on *Primary Care at 3am – emergency and out-of-hours care*, where it was clear that our collective knowledge of the extent of rising demand is far from complete and is hampered by a dearth of national research and by the shifting sands of changing definitions.

RISING DEMAND IN GENERAL PRACTICE

There are a number of problems in understanding this issue: first, studies are frequently based on one practice or a small geographical area, and there are wide variations between practices and areas; second, the definition of 'night' changes and the value of the incentive to report night visits (the fee) has risen. However, it appears that night visiting rates rose from 7–8 to 35 per 1000 registered patients per annum between 1973 and 1994.

Rising demand in A&E

Studies indicate that the rate of new attendances at A&E departments have more than doubled in the past 30 years. Around 40% of patients seeking care outside GP's surgery hours are seen in A&E departments. Some of the factors behind rising demand include:

cont.

- increased morbidity – there is no evidence to support the view that there have been substantial changes in the level of morbidity. However, there is substantial evidence that the simple appearance of physical symptoms is rarely enough to trigger a decision to seek medical advice.
- changes in perception of morbidity – information from the media may make people more aware of what symptoms might signify.
- social changes – these may reflect an extended market economy where people expect longer opening hours and more responsive services in other aspects of life. Also it is difficult for people who work long hours and feel insecure in their jobs to take time off work, and in the case of children, parents may not even know that their child is ill until the evening. Lastly, there may be fewer people to turn to for advice, and at the same time the implementation of 'care in the community' policies and an ageing population are also increasing the burdens that fall on both carers and primary care providers.
- supply side variables – there are few barriers to seeking care, and there may actually be perverse incentives to seek care outside surgery hours: fast service, no appointments, no direct cost etc.

'Inappropriate' use of services

Studies in A&E departments suggest that between 29% and 70% of visits are 'inappropriate', and studies of general practice suggest that 23%-32% of patients seeking emergency care are doing so unnecessarily. However, these figures do not reflect the views of patients, and very few patients deliberately misuse services, and they do believe that emergency advice or care is essential. Patients also have a firm idea of what is appropriate to take to A&E departments and what it is appropriate to take to a GP. Contrary to the common view of A&E staff, studies of new attenders in A&E generally find that patients have made no attempt to contact their GP, believing that he or she was not the appropriate person for their particular problem.

Source: Lesley Hallam, Research Fellow, National Primary Care Research and Development Centre, University of Manchester.

FACTORS AFFECTING THE NEED AND DEMAND FOR PRIMARY CARE FOR FRAIL ELDERLY PEOPLE

- Percentage of population dependent on social security will rise
- There may be less stability in family structure
- GP consultation rate will rise
- Hospital admission rates will continue to rise and length of stay will continue to fall
- An increase in 2% of funding will be required to maintain services at current levels

Source: Dr Jackie Morris, Consultant Physician in Medicine of Old Age, Royal Free Hospital, London

In the context of mental health, the issue was not just one of the volume of demand or a rise in demand, but the context of demand, given the transfer of services from hospital-based to community-based care. One speaker pointed out that most mental health problems are dealt with by general practice; this is viewed variously as 'keeping the lid on problems' or 'enabling people to live with their problems'. It is still a fact that most commissioner time is spent on hospital services, though most users use primary care most of the time.

Prioritisation

The question of managing demand inevitably led to discussions on prioritisation. It is in mental health that the arguments are rehearsed most obviously. National policy makes it clear that severe mental illness is the priority. On one level, few would disagree with that, given the severity of the distress of people with severe mental health problems, the consequences of serious mental illness to families and communities, and the high level of need for services. However, some of the discussion from primary care professionals indicates that the prioritisation of serious mental illness can leave primary care feeling isolated in so far as it may be primary care that cares on a day-to-day basis for large numbers of people who may fall outside of agreed definitions of serious mental illness, but who, nevertheless, are experiencing mental health problems and are in need of a great deal of help.

In the context of out-of-hours services, prioritisation was again an important topic. It is clear that there is more to prioritisation than the blunt instrument of whether the patient was seriously ill. The level of concern of the patient and their access to advice and treatment were also of great importance. In primary care, prioritisation should not just be a battlefield approach of first seeing those whose lives can be saved, but, rather, a more sophisticated way of ensuring that people get the kind of help that they need.

The workshop on *Primary Care at 3am – emergency and out-of-hours care* included interesting presentations on how assessments could be made on what kind of help was needed, and how it could be delivered in a way that was sensitive to need and to medical priority.

NURSE TELEPHONE TRIAGE

The subject of this presentation was the South Wiltshire out-of-hours project (SWOOP).

Context of the project

- Increased demands for health care
- 'Crisis' in out-of-hours primary care
- New development funding
- Growth of different schemes
- Limited evidence of their effectiveness and acceptability to patients.

Two key questions emerged from the work:

- How best to care for those patients needing the urgent attention of a GP?
- How to distinguish between those patients needing urgent attention from those who do not, and how best to care for those who do not.

cont.

What is nurse telephone triage?

Nurse telephone triage is a system in which experienced and specially trained nurses receive, assess and manage calls from patients and carers. The South Wiltshire scheme has some distinctive features. If the patient wishes particularly to speak to a GP, this is arranged, so it is a triage system with consent. Where appropriate, and based on protocols, calls may be dealt with by telephone advice, by GP referral or by expedited access to the 999 ambulance service.

Acceptability of the concept

In South Wiltshire there is a network called WREN – the Wessex Research Network of GPs, comprising about 180 GPs and community nurses. Before running the pilot project, it was decided to test out what patients might think about a telephone triage system. In partnership with Salisbury CHC, some focus groups were set up and a questionnaire survey of 500 households was administered. Of the 251 replies, 93% thought the proposed service would be an improvement and 97% were willing for their practice to try it.

Pilot study

The objective was to test out a nurse telephone triage service in order to look at the feasibility of running it and to obtain preliminary evidence of service quality. Practices were recruited and there was joint work on developing guidelines and protocols for telephone advice, including computer software and support systems.

The service was provided for 2 practices (for a total of 10,000 patients) and SWOOP ran 18 four-hour sessions, which was 1 in 9 of the out-of-hours sessions over a 6-week period. Letters were sent to every household across the two practices to explain what was happening. Incoming calls were diverted to the nurse, who had the telephone advice system support and the opportunity to have a 3-way conversation with the GP if necessary.

The nurse took details, made a nursing assessment, gave advice and faxed the triage decision to the doctor. Almost everyone who used the service was followed up by questionnaire within a week and was asked some specific questions about their experiences, satisfaction and preferences.

Results

- No major logistic problems were encountered
- 56 calls were received from 54 callers
- Most calls were non-urgent, and one-third had specifically called for advice/information.
- 21 calls were managed by the nurse alone
- Even where calls were referred to the GP, advice was often given by the nurse
- Nurse confidence (inferred from proportion of calls dealt with by nurse) rose as study progressed
- 35 calls were referred to GP, of which 12 received only telephone advice (same advice as nurse gave, but patient sometimes seemed to need a doctor's reassurance); half received a home visit

cont.

- There was broad satisfaction with both telephone interaction with the nurse, and telephone interaction with both the nurse and the doctor, and the majority were happy to speak to the nurse first and felt that the nurse and doctor worked as a team.

Potential benefits

For the patient
- Improved access to a professional dedicated to dealing with the call
- Consistent and high-quality service
- May encourage people who would delay calling

For the GP
- Possible reduction in workload
- Up to 50% of calls may be able to be managed by a nurse

However, more information on outcomes, more research and development are needed, and a randomised controlled trial is under way to test the safety and effectiveness of nurse telephone triage. An analysis of costs is also included in current research.

Source: Val Lattimer, Senior Research Fellow, Wessex Institute of Public Health Medicine

Socio-economic factors

One of the interesting reflections on bringing together a range of primary care professionals is that there is a high level of awareness of the importance of socio-economic factors as determinants of people's health and also of how they affect access to services and service use.

SOCIO-ECONOMIC FACTORS AND OLDER PEOPLE

- 33% of over-65s live in the lowest 25% of wealth band, and 39 % of over-75s live in the lowest 25% wealth band.
- In the over-60s, 19% of men and 42% of women live alone.
- There is a close relationship between the medical and social aspect of a disease. Disease can lead to impairment, which in turn can lead to disability.
- It is not sufficient just to provide social services – we need to provide services that actually meet people's needs.

Source: Dr Jackie Morris, Consultant Physician in Medicine of Old Age, Royal Free Hospital, London

For adolescents, speakers did not present statistical data, but many referred to the impact of socio-economic factors, for example, in relation to early smoking and accident rates. Also, some of the most vulnerable adolescents were or had been in care – a situation in which the socio-economic background was sometimes relevant.

There was an interesting discussion on how far primary care should go in attempting to deal with problems that were seemingly beyond the control of primary care practice, and where, it was felt, central government was actually undermining health promoting behaviour. The main example given was smoking, and Dr Ann McPherson expressed the following view:

'There is also the question of how far GPs see it as their role to take on trying to reduce smoking, when the government continues to permit cigarette advertising. Similarly, food policy is as important as GPs telling teenagers about healthy eating.'

The workshop on out-of-hours care also made reference to socio-economic factors, not least in terms of their effect on people's access to out-of-hours services. Many professionals seemed to favour primary care centre-based services, although patients without access to a car would find access difficult unless dedicated transport to the centre was made available. The need for out-of-hours care was also thought to reflect changing socio-economic situations. The vulnerability that many people feel in their employment may make them reluctant to take time off during working hours to seek medical care, and this may lead to a need out of hours. Higher numbers of working mothers may well be a factor in the need for out-of-hours care for children, particularly where parents may not even become aware of a child's illness until they return from work in the evening.

The workshop on mental health focused on the importance of socio-economic factors such as unemployment, poverty, discrimination, etc. These were seen to contribute to mental distress, and, therefore, social services, in the widest sense, were seen as important partners alongside health services.

Housing was particularly identified as an essential service for people with mental health problems. Housing was needed to cover the whole spectrum of housing need, from family housing and housing for single people, to supported housing and group homes for people who needed ongoing support.

- The condition and availability of housing is a key factor to people with mental health problems.
- The use of locally gathered information is crucial to appropriate joint purchasing decisions.
- Key workers need to be able to work across areas of concern, e.g. social services, education and health. This raises issues of confidentiality, but clients can be asked to give permission for professionals to share information.

Source: Julie Webb, Circle 33

It was clear from the discussion that primary health care practitioners, both as commissioners and as providers, had to develop highly sophisticated skills in working across boundaries. It was also implicit that even with the greatest possible level of inter-agency co-operation on the broader determinants of health, there remained a great need for policy and action from central government in proving a framework within which health and social care could be effective.

Chapter 2

Making change happen

Putting innovations into practice

Good ideas are not enough
A shortage of good ideas was rarely the explanation for a pace of change that was slower than most people would wish for. The sticking point was around how to put good ideas into practice in a practical and affordable manner. June Huntington, independent consultant in health care management and visiting fellow, King's Fund, made a useful distinction between invention and innovation, distinguishing between having an idea that works under laboratory conditions, and actually applying an idea at a reasonable cost in the real world.

Boundary roles and change
June Huntington explored some of the issues of 'boundary roles', where individuals are on the boundaries of organisations or systems and are therefore in a position to offer a different perspective from others who are more firmly embedded within a system. However, all too often the person with the boundary role has responsibility but no authority. The further the person moves from the mainstream of the organisation to its periphery, the less authority they tend to have.

Other speakers also had views on boundary issues and change.

- There is a need to shift professional boundaries so that services are not working in isolation from one another
- Boundaries between professions cause problems for patients, and patients benefit when such problems are overcome
- Different organisations should respect and make use of one another's strengths. For example, ambulance services have expertise in communications and IT that can be of service to other parts of health care.

Source: Laurie Caple, Chief Executive of Northumbria Ambulance Service NHS Trust

The following example also throws light on the process of change and boundary issues in primary care.

A CASE STUDY IN CHANGING OUT-OF-HOURS CARE

A GP co-op is a non-profit making organisation entirely and equally owned and mostly medically staffed by the GP principals of the area in which it operates. Before 1989 there were 4 co-ops, and some 10,000 GPs using commercial firms. The rest were doing out-of-hours work themselves or in rotas with colleagues. Many of them were experiencing rising demand, and were miserable, and many felt impotent about bringing about change. Commercial services were not interested at that stage in coming out of the conurbations.

cont.

Perceived disadvantages of co-ops

Lack of personal and continuous care from a known GP and absence of notes were of concern. (This latter point was rarely a problem, in fact, and IT developments mean that there are all sorts of new possibilities.) It was also felt that the existence of co-ops might stimulate demand. However, surveys of satisfaction disproved these concerns, and where there were co-ops, there were 'happy patients and happy doctors.'

Moving forward

The National Association of GP Co-operatives formulated 3 golden aims:

- abolition of the higher-rate night-visit fee penalty (which penalised doctors who were not doing their own on-call work);
- changes to the red book to clarify co-op funding;
- financial support for staff and premises.

In fact, health authorities have realised that they must talk to co-ops. GPs have realised that they worked. Patients are content. Politicians are keen. Commercial firms need to realise that they have little to fear. However, co-ops still needs academic validation and GP co-ops are keen to attract academic interest. Co-ops have taken off in a big way, rising from 500 GPs in co-ops in 1990 to 12,000 GPs in co-ops in 1996.

Co-ops are successful because the members are the owners, and they provide a service that the GPs are happy with. There is a team spirit, linked with primary care centres, and staff get to know the area. They are innovative, and there is room for co-operation with commercial services.

Location of co-ops

21% are urban
8% are purely rural
The remainder are mixed, usually based on a market town

77% of co-ops are situated in secondary care premises
14% are situated within primary care premises
9% are purpose-built

A typical co-op of 70 members will have 24,500 consultations in a year; will make 7577 visits; do 3660 consultations at base; and give phone advice to 13,286 callers. Training GPs in triage is important.

Source: Dr Mark Reynolds, GP and Secretary of the National Association of GP Co-operatives

What was evident from this presentation and from the general discussion that followed was that vested interests, both commercial and institutional, sometimes threatened the smooth path to innovation. Financial and administrative rules also sometimes supported an unsatisfactory *status quo,* or gave a perverse incentive to deliver less effective services. Equally important was the question of inter-professional trust and the need to learn new ways of multi-disciplinary working. Some of these factors are explored more fully elsewhere in the report (see section on 'Multi-disciplinary and multi-agency work' below).

At some of the workshops, there was discussion of possible levers and incentives for change. Some of the discussion seemed to take it as axiomatic that the incentive of providing a better service was insufficient to enable people to go through sometimes painful processes of change. Tim van Zwanenberg, Director of Commissioning and Primary Care Development in Newcastle and North Tyneside Health Authority, took the view that money (e.g. target payments, GP fundholding, prescribing incentive schemes, capitation payments) can be used to move people one way or another. It was not just hearts and minds that needed to be won, but important practical issues also needed attention.

Commissioner behaviour

The role of the health authority chief executive was seen as a very important one in creating the canvas on which practitioners could be creative. Susan Williams, Joint Chief Executive of Barking and Havering Health Authority, identified some necessary behaviours that commissioners need to adopt in order that change can take place. Her points were made in relation to mental health, but have broader relevance.

WHAT BEHAVIOURS DO COMMISSIONERS NEED TO ADOPT?

- Need to develop a strategic framework
- Get to know the providers and find the local champions
- Library function – it is important to learn from what is around
- Scope the task jointly
- Prioritise areas of attention jointly
- Assess levers and incentives – funding policies need to be in place to enable GPs to attend workshops; academic links can be effective; we can monitor purchasing for mental health services for fundholders through the accountability framework.
- Address the politics – commissioners need to spend time on mental health services, with MPs, councillors, etc., as they may have a traditional model of service in their heads
- Commissioners should enable providers to deliver confident services, and constantly to ask if the patient is safe in the system

Source: Susan Williams, Chief Executive Officer, Barking and Havering Health Authority

The role of GPs in making change happen

GP fundholding, total purchasing and locality commissioning were all presented as enabling change to take place and innovations to be introduced. It may be a reflection of the speakers selected, or of the context in which most change is taking place, but most of the discussion about how GPs could innovate and improve services was presented within the context of GP fundholding or total purchasing.

THE IMPACT OF GP FUNDHOLDING AND TOTAL PURCHASING (1)

Before fundholding, mental health was low on the priority list. GPs were not at all involved in priority setting, though GPs give mental health top priority for increased spending. We had an old, Victorian riverside hospital which was not particularly appropriate. We had excellent CPN support, but poor access to psychology.

We tried to clarify what we wanted to achieve through fundholding, and the following points were identified:

- fundholding is an integral part of the practice
- protection and development of under-resourced community and mental health services
- better access to secondary services
- adequate premises
- decompartmentalising funds to achieve the above
- ensuring work and resources accompany each other into the community.

Some of the changes that have been made in the field of mental health are reviewed below.

Reprovisioning mental health services

- Continuation of the very good CPN clinics
- A contract for a psychologist
- Direct employment of a counsellor and growing skill in using a counsellor effectively
- Building of an extension, providing room for the mental health team and a group room.

Source: Dr Rod Smith, Berkshire Integrated Purchasing Project

THE IMPACT OF FUNDHOLDING AND TOTAL PURCHASING (2)

Some changes relevant to services for frail elderly people as a result of standard fundholding:

- pathology collection services
- direct access physiotherapy
- domiciliary physiotherapy
- more community nurses
- improved community nursing service
- day case cataract service
- improved orthopaedic service
- improved access to out-patient services
- one-stop services
- outreach clinics
- increased communications between specialists and GPs
- development of primary care team.

cont.

In addition, the Total Care Project was instrumental in establishing the Discharge Liaison Team; although working in hospital, the team is based in general practice. The Total Care Project has also secured additional CPN time for each participating practice, in addition to the improvements to district nursing obtained through standard fundholding.

Source: Dr Michael Gocman, GP and Chair of New River Total Care Project and Dr Chris Jephcott, White Lodge Group Practice, Enfield

One aspect of debate that was under-explored in the workshops was the extent to which GP fundholding or total purchasing by GPs were in themselves the reasons for better primary care for particular client groups. It seemed beyond doubt that many innovations had come in through fundholding or total purchasing, but whether the freedoms that those structures allowed or the enthusiasm of the individuals involved gave the fullest explanation for change was left unaswered. What did seem to be very important was that GPs needed to be involved in strategy.

Primary care as part of a system supported by specialist services

Throughout the workshops there was a good deal of attention given to issues of generalism and specialism. The notion of an ideal primary care service was one where generalists in primary care were responsible for most care, supported by appropriate specialist services. Specialists could be responsive by meeting more complex needs, through consultation, assessment and management. The potential for offering support in new ways was exciting in the light of actual and potential advances in technology.

Dr Stephen Miles, Consultant in A&E at the Royal London Hospitals, noted an increasing trend towards greater degrees of specialisms. In discussing the role of A&E in out-of-hours primary care, he remarked that:

'A&E is hospital-based primary care, and general practice is community-based primary care. Both are the last remaining generalists in the NHS.'

The generalist in primary care was seen by some as a kind of specialist. Though it may sound paradoxical, generalism is in itself a specialism, since it requires such a broad range of clinical and diagnostic skills, as well as a vast range of knowledge on where to find specialist help, both clinical and social. The holistic approach that tended to be favoured in primary care, was one that was borne of a generalist perspective and was much harder to maintain in the face of growing specialisation.

PRIMARY CARE FOR MENTAL HEALTH – THE INTERFACE BETWEEN PRIMARY CARE AND SPECIALIST SERVICES AND SOME PROBLEMS IN THE SYSTEM

- Both primary care and specialist services are under pressure, and there is a lot of anxiety about getting things wrong

cont.

- There is a lack of established processes for collective working. For example, GPs feel unable to influence the shape of specialist services; specialist services feel they have difficulties in discharging patients; communications may have been poor; there has tended to be more emphasis on shunting problems than sorting them out
- There is often no framework for joint needs assessment or service review
- Mental health has not been an early priority for most commissioners, either GP fundholders, or health authorities, who have had to prioritise other needs
- In some instances, primary care staff have insufficient expertise in modern mental health services. This needs to be addressed through multi-disciplinary training.
- Many practices have not been able to provide an infrastructure to ensure systematic and proactive care
- There are difficulties within primary care in accessing specialist services
- GPs may feel they are left with the out-of-hours problem

Source: Dr Sheila Adam, Head of Mental Health and NHS Community Care, DoH

The need for flexibility in contractual arrangements

The King's Fund workshops overlapped with the publication of *Primary Care: the future* and the White Paper, *Choice and Opportunity – Primary care: the future* in October 1996. The flourishing volume of debate that had flourished around primary care had strengthened the feeling among many people that what was needed for real change to take place was intervention at the highest level to promote new ways of working. The possibility of local contractual arrangements was seen as an exciting opportunity, but it was also felt that lessons from the past should be learned, and there should be no headlong rush to change. The need to build on pilot projects and to evaluate results was thought to be paramount.

The growth of evidence-based practice that was occurring in relation to clinical effectiveness was thought not to have been matched by a similar rigour in managerial and organisational matters, and there was a view that it should be. Evaluation of the consequences of new contractual freedoms needs to be more than an examination of whether a new way of working actually works in principle. It also needs to address the question of what works best. Issues of acceptability to patients and cost-effectiveness feature large in these considerations.

Multi-disciplinary and multi-agency work

One of the greatest challenges in primary care is the development of new ways of working that transcend professional boundaries. This approach is often referred to as 'multi-disciplinary' working, though other work, including King's Fund work on multi-disciplinary public health, indicates that people's understanding of the term 'multi-disciplinary' can differ greatly. Often, it was multi-agency work that people regarded as a factor that improved primary care.

A multi-disciplinary/multi-agency approach involves a number of key features which are relevant to primary care. These are explored below.

Information sharing across professional groups and agencies

Dr Kathie Binysh, Senior Medical Officer, Department of Health, suggested that, in relation to the Health of the Young Nation, a lot of high-quality work is taking place across the country, but people are often not aware of what others are doing, even where they are geographically close. The Adolescent Health Network (now called the Young People's Health Network) was a response to that need. She also described collaborative work with those concerned with education, such as the European Network of Health Promoting Schools, and a wall chart for schools, in collaboration with the Department for Education and Employment. The Department of Health has also included information about Health of the Young Nation in a RCGP/BMA pack for GPs about how GPs can contribute to the aims of Health of the Nation.

Dr Sheila Adam stressed that effective multi-disciplinary work in primary care needs to be underpinned by appropriate information systems, with information about individual patients made available between agencies on a confidential 'need to know' basis. In a similar vein, Judi Clements, National Director, MIND, stressed the need for information exchange both between different parts of the same service and between different services.

AN EXAMPLE OF INTER-AGENCY WORK: SERVICES FOR CHILDREN AND ADOLESCENTS

- There is a need for different agencies providing services for children and young people to work together. If this is achieved, the effect is not merely additive, but synergistic.
- The pattern of care of children and adolescents with special needs can be very complex, and may vary according to the way in which a need first presents, rather than according to the child's problems.

The role of the GP and the primary care team in the care of children and adolescents vary a great deal. Often, the GP will have been involved in the recognition of presenting symptoms or signs earlier in childhood. The relationship will be different if this has happened as a result of routine child surveillance, when the health visitor may also have been involved. Under the Special Educational Needs (SEN) Code of Practice, if the condition is noted when the child is at school, referral may be made to the health authority designated medical officer and, although the GP may be informed, he or she may or may not become involved in care. The SEN Code of Practice is well structured and a number of sections acknowledge that the role of the GP can be variable. The GP may be bypassed if an infant is followed up from birth by the neonatologists and passed on to a hospital paediatrician or other specialist. Unfortunately, a number of good initiatives such as the One Stop Shop type of centre, run jointly by the local authority and health services, effectively exclude the primary health care team.

Source: Dr Zarrina Kurtz, Consultant in Public Health and Health Policy

Multi-disciplinary work is more holistic

While all people benefit from multi-disciplinary work, the case can often be seen particularly clearly for young people. The services described by David Tait at Base 51 in Nottingham are popular because, being user-centred, they do not allow professional boundaries to stand in the way of service delivery. Young people may use the service for its nursing, medical or counselling input, or as a resource from which they can obtain information.

Leadership of multi-disciplinary work

It was clear from discussion that there is a need for leadership in multi-disciplinary working, and it is not always clear where this is to come from. Leadership by an individual could sometimes be seen as promoting the primacy of that individual's profession, and would not be seen as promoting a multi-disciplinary approach.

Multi-disciplinary training

The benefits of multi-disciplinary training were suggested by some, including Dr Sheila Adam of the Department of Health. Multi-disciplinary training could involve not only members of a NHS primary health care team, but also professional colleagues in local authority social services, or the voluntary sector. A multi-disciplinary approach to training could have several advantages. It would:

- provide a forum for different disciplines to learn from one another
- promote better knowledge of services across different agencies in a locality
- promote a better understanding of one another's professional roles
- facilitate smoother working relationships by enabling people to get to know one another
- be cost-effective, sharing the expenses of training between professional groups and between agencies.

It is important that 'training' in a multi-disciplinary context is not construed too narrowly. Susan Williams described how a colleague in Barking and Havering Health Authority had commissioned a local drama group to dramatise the findings of the Clunis report. This has been very effective, provoking different reactions in different kinds of groups, and enabling people to understand the importance of multi-disciplinary teamwork.

Morale

Taking the workshops as a whole, there were a series of mixed messages on morale, from wild optimism and product-championship for particular ways of working to a sense of weariness and pressure. Needless to say, such polarities could be contained within one person, as well as reflecting differences between people.

One of the major threats to morale seemed to be a feeling of relentless pressure on services, combined with an equally relentless need to keep costs down.

Judi Clements, National Director, MIND, made the following observation:

'I have heard repeatedly from health professionals and academic commentators that morale in general practice is at its lowest point for 30 years, that workers in primary care feel that they are being 'dumped on' and that the expectations that are being placed on them are not coupled with the resources needed to realise these expectations.'

Judi Clements also noted that the gatekeeping role of primary care might put particular pressures on primary care staff, with primary care workers charged with limiting demand.

Another possible cause of low morale could be the continuing status hierarchy within medicine, which, in some instances, continues to accord primary care a low rung on the ladder.

> Many hospital doctors have stopped seeing GPs as being doctors who fell off the career ladder for hospital medicine. But I would contend that their view of what is important or serious remains unchanged, and when the chips are down about what should get the money. It is still treatment of acute disease episodes or trauma that counts. Their currency is the completed consultant episode and in many ways the idea of continuing care is entirely peripheral to their interests unless patients begin to 'block beds'. Even very junior hospital doctors feel able to challenge an experienced GP's definition of what is urgent or serious. Just last year, I heard teaching hospital consultants engaged in curriculum development talk about 'the trivia seen by GPs'.
>
> *Source:* Diane Plamping, King's Fund Fellow in Primary Care

Diane Plamping also made the point that the level of understanding on primary care is patchy, even among those holding public appointments (for instance, a chair of a hospital trust is reported to have asked, 'Primary care – is it like primary schools, the beginner stuff?') It remains true that many people understand primary care mainly through their own experience of general practice. Even the majority of people with political power may have little experience of other primary care services and other models of working. This lack of understanding may lead to an undervaluing of primary care, and a consequently low level of morale among its practitioners.

Dr Plamping went on to say that hospitals continue to symbolise what the NHS is really about. Local authority members still sometimes talk about shifts of investment to general practice as taking money out of the NHS (i.e. they see the NHS as being about hospitals and not GPs). Indeed, parts of primary care have all but disappeared from the NHS – dentistry and opticians, for instance.

The importance of personal contacts and personal enthusiasm

Effective work in primary care, particularly when it is multi-disciplinary, relies heavily on individual effort. The importance of leadership has been mentioned elsewhere in the report. This section highlights the role of individuals in making a difference to primary care, whether or not they are in a leadership role.

Many of the speakers, and a good number of the other participants, were personal examples of commitment and enthusiasm. (Paradoxically, this seemed to be the case even when low morale was under discussion.) The role of the individual practitioner could be important in a number of ways:

- by demonstrating that obstacles could be overcome
- by advocating a particular approach and securing it funding
- by supporting staff who had doubts and difficulties in making an approach work

- by being clear and consistent in their vision of a service
- by making and developing effective working relationships with others, thereby fostering a spirit of trust and co-operation.
- by having a sense of realism about what can – and cannot – be achieved

The conference presentations described primary care in various settings, where a range of structures were in place. Some services were located in or provided from a community trust; many were under the umbrella of general practice; others, like some of the out-of-hours services, were operating from acute hospital premises. Flexible and appropriate organisational structures can facilitate good primary care, and rigid and inappropriate structures can undoubtedly impede it, but it is the individuals within those structures who appear to be most important.

Hospital and alternatives to hospital – a spectrum of care

Since primary care is chiefly about what happens in or near people's homes, there was a great deal of discussion on the place of acute hospitals in the spectrum of care, and the range of alternatives to hospital-based care. Though it may be an obvious point, it bears repeating that no primary care system can take care of all health needs for all people. A health service is as good as its weakest links, and just as acute services can be undermined by inadequate care in the community, so primary and community services can be let down by hospital services that are inadequately resourced or poorly managed.

Public fears of changing from 'hospitals that they can see' to 'primary care that they cannot see', and at times is more promise than reality, naturally cause anxiety.

> Many people fear that any change in service provision is just a novel way of repackaging a cut. Neither are most politicians and citizens convinced that the often unimpressive primary care facades will 'substitute' for the safety they perceive to lie within the more impressive institutions – the hospitals. 'Will GPs who want to 'have a go at surgery' do a better job than specialists?' or ' Are we being fobbed off with treatment by a nurse?' are both questions I have been asked repeatedly by the media as examples of people's concerns. Indeed a primary care centred NHS would be one in which the production process (both people and plant) would be found in different places and implies investment in a reconfiguration programme for primary care every bit as immense as that facing hospitals. Yet answers to parliamentary questions reveal that the London Implementation Group spent more on so-called 'transitional funds' for hospitals than on the London Initiative Zone investments – and this in a city in which a long history of under-investment in primary care is uncontested.
>
> *Source:* Diane Plamping, King's Fund Fellow in Primary Care

Given the need for adequate investment in primary care, and the recognition that this has, so far, not occurred as widely as it should, there was great interest in hearing the details of examples to alternatives to hospital. The following presentation provides an interesting example.

AVOIDING HOSPITAL ADMISSION FOR ELDERLY PEOPLE – PURCHASER AND PROVIDER PERSPECTIVE

This presentation described the local context in Redbridge and Waltham Forest and the development of a hospital at home scheme. The demographic changes, with a rise in the 85+ population, and a slight rise in 1995 in the 75–84 age group after a period of decrease, were described, showing a similar pattern to elsewhere. A census of people attending A&E showed that 28% were over 75 years, and of that age group, 57% were admitted to hospital from their visit to A&E. A census in the Department of Medicine for Older People looked at over a hundred admissions and found a large number occurred where people had had a fall, for example, and had lost confidence, rather than having a specific illness. The census also showed a high readmission rate in older people. All in all, the motivation for change included:

- a joint agreement to develop primary and community services
- pressure on A&E and inpatient services
- local information about reasons for admission
- nationwide information and experience.

In developing services, it was necessary to make changes, matching skills to need, and addressing the manifestations of the inverse care law in community services, i.e. the greatest amount of care is delivered where it is least needed and vice versa. The Hospital at Home Scheme was seen as one of the approaches that could make a difference. It developed for the avoidance of hospital admission, and not just to promote early discharge. Originally, the scheme was to be called a 'primary intervention service', with a health promotion approach. However, as part of the LIZ scheme, there was some pressure to call it a hospital at home scheme!

About the Hospital at Home Scheme

The scheme was set up in September 1994 in just six weeks.

The aims of the scheme are:

- to prevent unnecessary hospital admission
- to facilitate earlier discharge from hospital where appropriate
- to increase choice for the patient and carer as appropriate.

The admission criteria are:

- the patient lives in Waltham Forest
- the patient would otherwise be admitted to or remain in hospital
- the patient's GP will accept medical responsibility
- the patient is over 16 years of age
- the patient/carer consents to the scheme
- the patient's clinical condition is safe for care at home
- the patient has a safe and suitable environment for care when adequate health and social services input is provided

- the patient's needs/treatment will be met within 2–8 weeks as appropriate
- the necessary hospital at home resources are available.

Hospital at home schemes must have operational policy covering the following:

- hours of operation
- referral procedure
- team location
- response time to referrals
- patient/carer/GP consent
- equipment usage.

The staffing of the scheme is multi-disciplinary, including occupational therapy, district nursing, physiotherapy, staff nurse, rehabilitation nurse and patient aides. Staff work flexibly, sharing skills and assessments. Relationships with social services are good. Although the scheme may need more social services input at times, successful rehabilitation reduces demands on them at other times.

Training is essential for the successful running of the scheme and includes:

- in-house training for staff
- hospital at home awareness
- specialist training
- study days and conferences.

Of the patients admitted, most were elderly, and many were age 85+. Diagnosis on admission to the scheme covered a wide range, including acute admissions, acute or chronic illness, arthropathy, cancer, cardio-vascular accidents, falls, problems in mobility, orthopaedic problems and terminal care.

Problems that schemes can face

- Under-utilisation
- Seasonal variation in referral
- Over-treatment
- High readmission rate
- Poor functional outcomes.

How successful is the scheme?

- The scheme is popular, and local cynicism has diminished
- There has been a positive evaluation which recommended that the scheme be continued and developed
- There is a need to demonstrate cost-effectiveness

Source: Helen Fentimen, Director of Primary Care and Community Care, Redbridge and Waltham Forest Health Authority and Michele Sappa, Director of Primary Care, Forest Health Care Trust and Dawn Land, Co-ordinator of the Hospital at Home Scheme

Conference participants had experiences of their own of hospital-at-home schemes, and it was plain that there are a number of differences in the way that schemes are set up and run, as well as broad similarities in what they are trying to achieve. One significant area of consensus was that an effective and safe hospital-at-home scheme could be popular and achieve what it set out to do, but could prove to be expensive, and the need to investigate and demonstrate cost-effectiveness remained a live issue.

The spectrum of care includes both innovative and established services. In addition to learning about innovation, it was also useful to hear a summary of the role of nursing for frail elderly people.

THE ROLE OF NURSING IN PRIMARY CARE FOR FRAIL ELDERLY PEOPLE

Shropshire is a large geographic area, with a population of 450,000 with distinct rural and urban elements. The boundaries between health and social services are coterminous and joint strategic and policy approaches have been developed, with evidence of inter-agency collaboration and joint purchasing. Shropshire has two medium-sized acute district general hospitals, one specialist orthopaedic hospital and four community hospitals within the community trust. Primary health care teams are devolved to the level of general practice populations, and there is evidence of joint management. Primary health care nursing teams are led by a team leader who reports to the lead GP.

Working with frail elderly people – guiding principles

There is a need to:

- improve and maintain the quality of life
- allow people to remain as independent as possible, and intervene when necessary by consent
- provide effective intervention and advocacy at key times, e.g. hospital admission and discharge.
- be responsible often as part of a 'collective' to review and evaluate the care packages and their appropriateness
- be prepared to shift the boundaries of professional roles in order to meet the various needs that arise
- acknowledge and act upon the exceptional vulnerability of this patient group.

Nursing – key aspects of the role

Nursing has a key role within the concepts of care in the community and a primary care- led NHS. It has an obvious role in assessment, planning, implementation and evaluation of care, and has a contribution to make for the development of services for elderly people. Nursing has an obligation to use financial and human resources properly and efficiently, and it has a duty to work in collaboration with others to best plan and deliver services for elderly people.

cont.

What do we define as primary care?

In Shropshire, we include some elements of our community hospitals, and the potential that they may have for further development.

- GPs are part of the hospital medical staff
- Inpatients are largely drawn from their practice populations
- GPs have the ability to use the beds flexibly, e.g. GP admissions, rehabilitation, and early discharge from acute facilities
- Nurses play a major role both in hospital and at the discharge interface – there is a continuum with primary care, and work is under way to explore nurse admission and nurse-led care
- Community hospitals are already the base for primary care emergency centres and an out-of-hours co-operative
- Community hospitals will play an increased role in relation to emergency bed planning in the acute sector

Nurses and the primary health care teams

One of the features of our organisation is a devolved primary health care team (PHCT) model. This means that nurse members of the PHCT work to a dedicated practice, in the case of GP fundholding practices, or to a regular grouping of GPs in other cases. They are led by a team leader, who is employed by the trust, and most of the management function, including some aspects of recruitment and training, is devolved to team leaders. The devolved PHCT model has led to closer co-operation between nursing staff and GPs and has increased the joint ownership of issues. Joint priority setting and resource targeting have been made easier by nurses being dedicated to a particular practice population.

Most new nursing developments have evolved from the 'devolved model', e.g. the introduction of discharge liaison nurses. In addition, nurses have become more involved with screening procedures for elderly people, and some practices have 'employed' specialist staff for specific work with elderly people. This model has implications for other groups, and could be extended to other services such as physiotherapy. While devolved management has to be exercised through a trust employee, future flexibilities in organisational models, if they occur, may open the way for other innovatory management models.

The role of nurses is wide, from assessing and reviewing packages to supervising the work delegated to others delivering the care. There are also some joint appointments for nurses with social services.

In summary:

- the nursing role has changed radically from hands-on provision to case management and education
- nursing now has many opportunities to influence the future shape of service delivery for elderly people

cont.

- nursing also faces threats, such as duplication and overlap of role and there are competitors for the provision of services
- nurses are in a unique position to advocate for fully meeting patients' expressed and implied needs.
- Community care and a primary care-led NHS will increase the pressure upon community nurses, but also provide the vehicle for influence and change
- nurses should consider the role they may have in joint commissioning; they are in a unique position to advocate
- nurses need to develop ways of measuring their outcome in a more meaningful way.

Source: Jo Hesketh, Director of Nursing and Quality, Shropshire Community Health Services NHS Trust

The development of the nursing role in primary care was a recurrent theme throughout the series of workshops, and their role out of hours was seen to be very significant. Hearing a nursing perspective was a salutary reminder that out-of-hours care is not just emergency care; it is also routine care, taking place day after day and night after night, often carried out by families and friends rather than by professional health care workers.

THE CONTRIBUTION OF NURSING TO OUT-OF-HOURS CARE

The development of a 24-hour district nursing service

This presentation looks at a 24-hour district nursing service in North Staffordshire. We will look at the service and its costs, the range of activity and future opportunities and also at the contribution of nursing in general, both in support of medical practice and as a substitute for medical practitioners.

The North Staffordshire Combined Healthcare NHS Trust provides services for elderly care, mental health, learning disability and primary care. The contract income is £70 million. In the primary care directorate there are 800 staff and the contract income is £17 million. GP fundholders cover 53% of the population.

The area covers a population of 460,000, in both urban and rural districts, over 450 square miles. We have a combination of all kinds of challenges, and if it works in North Staffordshire, it could work anywhere! We have two bases, one in a city centre, and the other in the central moorlands.

The service works in four shifts: 1700–0100; 0100–0700 with an overlap from 2100–0100; 0630–0930; 2130–0700 (nursing auxiliary sitting service).

Requirements for evening and through-the-night services:

- a nursing network which has close and clear communications networks with primary health care teams and other support agencies. It is important to complement PHCTs, not to run a parallel system

cont.

- an appropriate mix and development of skills to meet care needs
- sufficient staff numbers for the territory and the population.
- development of skill mix and clinical competency
- arrangements for the safety of staff
- a comprehensive rapid communication system to ensure a timely response to referrals – we use radios and phone and have clerical support until 10pm
- access to equipment to assist patient care and support
- specialist nursing support, training and development – it can be lonely work and we need a particular kind of staff.

Human resources

The service has 50 people, equivalent to 37 full-time staff. It is managed by a primary care manager in an 'extended portfolio role'. The manager also has responsibility for the Marie Curie service.

Costs

The service is not cheap, and costs a total of £840,000, of which £710,000 is pay costs. In contrast, a 28-bed medical ward costs about £500,000.

Range of activity

- Chronic and enduring ill health/disability
- Terminal and palliative care
- Post-operative day surgery
- Emergency genito-urinary/accident and emergency referral, including catheterisation
- Oncology, including phoning patients after chemotherapy and radiotherapy and providing intra-muscular anti-emetics
- Paediatric

Between June and September 1996, the caseload analysis was as follows:

0–15 years	**8**
16–55 years	**103**
56–65 years	**56**
66–75 years	**99**
76–85 years	**122**
Number of patients	**456**
Number of contacts	**8434**

13% of visits took 30 minutes or more, and 26% required two members of staff. The 76–85 age group took up 29% of time.

cont.

Future opportunities

- Rapid response
- Expansion of palliative care
- Collaboration with medical out-of-hours arrangements
- Paediatric service

In summary, nurses have always has a large role in the support of medical practice. There is also a growth of nurses as substitutes for medical practitioners, and an increase in the number of nurse practitioners and the development of specialist roles are interesting developments. However, nurse-run services are not cheap and the need for appropriate use of time out of hours is no less relevant for nurses than for doctors.

Source: Alison Norman, Exectuive Director of Nursing and Primary Care, North Staffordshire Combined Healthcare NHS Trust

Chapter 3

Improving primary care

Communication and information

The need to share information has already been discussed under the heading of multi-disciplinary work. Multi-disciplinary work makes information sharing essential, if different members of a multi-disciplinary team are to make an informed and collaborative contribution to patient care. However, as primary care takes a more prominent part in the overall configuration of care, the need to develop robust information systems becomes ever more pertinent. This was a preoccupation of many of the participants across the whole series of workshops. Some of the reasons for the need for improved information are:

- to avoid duplication of care
- to ensure safe, high quality and consistent care
- to assist the development of 'seamless services'
- to enable audit of treatment and care to be carried out.

In the case of individual patients they include:

- to assist patients to see their records in accordance with statutory rights.

There are also difficulties in bringing about the necessary changes to enable information sharing, both about patient care and about facilities and service developments, and such difficulties are exacerbated where there are organisational boundaries as well as professional boundaries to be negotiated. The issues that require more discussion and then action include:

- how can patient confidentiality be safeguarded while increasing the sharing of information?
- who needs to know what information?
- what information systems are available, appropriate and affordable to use?
- what systems are best suited to a range of work settings, e.g. hospital-based, clinic-based, domiciliary care-based, etc.?
- what are the training implications of improving information?
- how and to what extent can voluntary bodies be included in information networks?

Manual and electronic information systems can all be improved, and technology is changing all the time. However, one thing that does not change is the paramount need for people to talk to one another. Attitude may be as important as technology in enabling good communication to take place, but organisational barriers may deter individuals from talking together, particularly if there may be a competitive edge to relationships between the organisations in question.

Several people observed that even where there was a general willingness to share information locally, there was often an inadequate level of knowledge about what colleagues actually did or how they saw their respective roles. Financial and administrative support for newsletters, networks and informal structures that enabled people to share information were all welcomed.

THE NEED FOR IMPROVED COMMUNICATION AND INFORMATION FOR BLACK AND MINORITY ETHNIC COMMUNITIES

Communication and information are issues for everyone, but there are particular concerns about Black and ethnic minority communities:

- there is a need to enhance professionals' awareness of minority ethnic health issues
- there is a need to provide access to a trained advocacy and translation service
- Black and minority ethnic communities need to be made more aware of the services that are available

Source: Judi Linney, Health Promotion Service, West Surrey Health Authority

Education and training

The call for better education and training, including practice-based education, was a frequent and often plaintive cry. When services were functioning at a less than optimal level, and particularly where there was an apparent inter-personal or inter-professional difficulty, the call for improved education was never far behind. Perhaps education and training were seen as panaceas, when problems also needed a more focused management, or an appropriate share of resources. Be that as it may, the need for education was clearly a very pressing one, and the need was expressed in several different ways:

- education as a spur to changing practice
- the need for education at all stages of professional life
- the need for practice-based education and training
- the need for educating the public.

These are explored in turn.

Education as a spur to changing practice

Tim van Zwanenberg asked some interesting questions at the June conference about what makes change happen in primary care as a whole.

'So what makes change happen? The first one is education. But the evidence that education makes any difference to patient outcomes is virtually nil, usually because it has not been looked for, or where it has been looked for, there is no effect. There is some evidence that you can change practice with guidelines, which is another form of education. It seems to be more effective if it is targeted at opinion leaders, whoever they are.'

However, with or without evidence, it seemed to be a basic tenet in the series of workshops that education had the power to alter views, shift priority and influence practice. A reminder that we would benefit from a deeper understanding of how and in what circumstances education is most beneficial to developing primary care is a useful one.

The need for education at all stages of professional life

Dr Sheila Adam made the point that primary care in mental health needs to be underpinned by education and training, pre-qualification and post graduate training, multi-disciplinary training, practice-based training and integrated training across primary and secondary care

The need for practice-based education and training

Dr Adam and others felt that there was a need for explicit focus on practice-based education and training for those working in mental health. There was considerable support for the view that this need extended far beyond GPs and must include all members of the primary health care team. Indeed, in mental health, properly trained receptionists could be as vital as properly trained GPs. Training for practice nurses and all the generalists in primary care was necessary, as well as improved training for mental health specialists.

Combined Healthcare NHS Trust signalled the need for specialist nursing support, training and development for nurses working in the community on evening and night work. The specific demands of their job, and the loneliness of their position made support, training and development essential.

Some primary care professionals had an educational role to professional colleagues, as Huw Meredith, Development Director, Dementia Relief Trust, and Debbie Williams, Admiral Nurse, Riverside Mental Health NHS Trust, explained about the role of admiral nurses.

'Admiral nurses are specialist nurses working in the community as part of the NHS. They engage in casework with carers and people with dementia, making assessments, facilitating service provision and advocacy and offering emotional support. They also provide a consultancy role for other professionals, and offer casework support, education and training.'

The need for educating the public

There are several aspects in which the public may benefit from education about primary health care. First, as primary care is largely delivered in or near people's homes, the burden of care often falls heavily on family and friends and indeed as self-care by patients themselves. Health care professionals in primary care have long recognised their educational role to facilitate self-care and care by lay people. Perhaps what is new is a greater recognition that this principle can be extended to improve public understanding and ability to cope with even very serious conditions which would have required hospitalisation even a short while ago. This applies equally to both physical and psychiatric conditions.

Susan Williams, Joint Chief Executive at Barking and Havering Health Authority explained that part of her health authority's response to the Clunis Report was a programme for managing serious mental illness in general practice. In addition to including a disease register, a call and recall scheme, a structured review, practice audit and a crisis plan, there was also education and support for the family and individual. It is worth remembering that there is a financial cost to providing this kind of education and support, and in the case of this initiative on severe mental illness, the whole scheme in general practice is reimbursed in a similar way to paying for management of asthma and diabetes.

The second sense in which the need to educate the public was discussed was the value of ensuring that the general public (and professionals too) were given as much information as they needed in order to best use available resources and services. The need to reach out to individuals and communities who may have been overlooked with regard to accessible information is vital.

Related to this, but different and more controversial, was an implicit rather than explicit view that the public needed educating so that they could see things as professionals saw them! Thus, patients who persisted with the view that their communities needed more hospital beds were perhaps seen by some as in need of education, or perhaps in the spirit of the Chinese Cultural Revolution, of re-education.

In similar vein, in the context of rising demand for out-of-hours services, for example, while the prevalent view supported the primacy of the patient's own definition of what was an urgent need, there was also a significant view around that if demand and resources did not fit, a useful approach was to educate patients into redefining their needs and making fewer, or at least different, demands. The issues raised about power sharing and who should define the agenda for health are central to debates about educating patients. Few would oppose better information and better education for lay people, but the point at which patient education becomes pressure or propaganda is the point at which health care workers would be exceeding their professional brief.

Evidence-based practice

In primary care, as elsewhere in the NHS, there is growing consensus that practice should be evidence-based. This applies equally to clinical practice, to policy and to management and organisational issues.

One problem, particularly where people are motivated by an urgent desire for change, is the possibility that if a particular scheme is able to function at all, that may be mistaken for evidence that it works well or is the best available model for service delivery.

Moreover, the commitment to evidence-based practice may be undermined by the need to get services up and running in a very tight time scale. In the current climate, one consequence of a measured, evidence-based approach could well be that an opportunity to secure funds is missed, or that a self-evidently non-evidence-based service or organisational model is allowed to persist. Arguably, the solution to this dilemma is in the hands of those who take funding decisions, but they too are keen to seize the opportunities that may arise from windows of political opportunity.

Urgency is often part of the real world, and the consequences of failing to grasp nettles may be worse than the sting of grasping them. so the question is what can be done to move towards evidence-based practice (clinical and other) as fully as possible? Some of the clues to this problem are to be found in better research and dissemination of research findings, and the need for better research and development was a theme that permeated all the workshops in the series (see below). Other ways to increase evidence-based practice include:

- clearer definitions of what would constitute a successful outcome, and what would be acceptable as evidence, including a more central part to be played by users' views
- more use of pilot schemes
- an honest approach to evaluating the benefits of innovation that recognises the value for development purposes of projects that do not have wholly positive evaluations
- a 'safe' working environment where risks are encouraged at best, or at least tolerated
- improved dissemination of the results of pilot schemes and local innovations in order to share learning across the country.

Perhaps one of the keys to moving towards an evidence-based approach is the recognition that there is a tendency to assume that a common-sense or gut feeling about something is actually evidence. It may seem self evident that counselling or nurse telephone triage in out-of-hours care, or community mental health teams, or primary care centres are good ideas. However, those involved in such schemes are the first to accept that widespread adoption of innovation requires evidence rather than prejudice to support it, no matter how optimistic and well intentioned prejudice may be.

Finally on this point, the paradox is that a commitment to evidence-based practice may actually allow greater risk taking, and a greater willingness to try out truly radical ideas. This is so because the safety net of evaluation gives permission for a trial of ways of working that are not certain to succeed.

SEEKING THE EVIDENCE – AN EXAMPLE OF AN EVALUATION OF A COUNSELLING SERVICE

The mental health workshop heard about the evaluation of the Dorset Primary Care Counselling Service. This is a Psychology Managed Counselling Service, where the counsellor is selected and employed by the Psychology Service, and works in 1 or 2 practices. GPs refer directly to counsellors.

The key questions for the evaluation were:

- What is the effect of counselling on psychiatric symptoms, self esteem and quality of life?
- What do counselled clients think of the service?
- Does the counselling service affect referrals to psychiatry, psychology, CPNs, etc.?
- Does the counselling service affect prescribing of anxiolytic/hypnotic and anti-depressant medication?
- What do GPs think of the counselling service?

Some key findings from the evaluation

- The main causes of clients' problems were relationships with partners, bereavement and work related issues. Problems were not trivial or minor, though they may not fit easily into a psychiatric diagnosis.
- The number and severity of psychiatric symptoms improved to a highly significant degree during counselling.
- The follow up at 6 months indicated that improvements in psychiatric symptoms continued after counselling finished.

cont.

- Client self esteem improved during counselling, with no deterioration found at follow-up.
- Clients experienced highly significant improvements in work, home management, social life and leisure, but not in family or sexual relationships.
- The opportunity to talk to a non-judgmental professional was most valued. The most common negative comments related to counselling style.
- 84% of clients were satisfied with the counselling service.
- There was a highly significant reduction in prescribing of anxiolytic/hypnotic medication from 1992-1994, but no difference whatsoever between practices with a counsellor and practices without a counsellor.
- Psychiatry out patient referrals have steadily and significantly declined between 1992 and 1994, but there was no difference in this decline between practices with a counsellor and practices without one. In patient trends, which rose from 1992 to 1993, then declined from 1993 to 1994 showed no difference whatsoever between practices with a counsellor and practices without a counsellor.
- GPs were all satisfied with the counselling service, and 86% thought there was a difference between what a counsellor and a psychologist could do.

Source: Helen Allen, Dorset Research and Development Unit, Bournemouth University

Research and development

Research and development are part of the foundations of evidence-based practice and there was considerable interest throughout the workshops in research and development that was relevant to primary care, both in terms of process and outcome. This interest can be summarised under a number of headings.

A wide view of research
In a narrowly construed notion of research, the pinnacle of methodology is seen as the Randomised Control Trial (RCT). However, in the real world of people and organisations, carefully controlled trials of what works in the organisation of primary care may be neither achievable nor universally relevant. A wide view of research, employing a range of methodologies alongside RCTs, is called for. Action research and consumer focused research are also important. Research on what is acceptable and appropriate for patients is as important as research on clinical effectiveness, though it goes without saying that neither concern can be overlooked.

Funding for research
Research does not come cheap and adequate funding for research is essential. In addition to local research initiatives, support for research at a more central level is required..

The National Primary Care Research and Development Centre is a Department of Health funded centre based in the University of Manchester with links to units in Universities of York and Salford. It is unusual in relation to Department of Health research funding, in that the Department of Health has agreed up to 10 years funding on a rolling basis, subject to major reviews to ensure the quality and responsiveness of the work.

cont.

Aims of the National Centre:

- to deliver high quality research
- to disseminate research findings and promote service developments
- to contribute to meeting research needs throughout the service and to promote effective health service research into primary care through the training, development and support of researchers.

Source: Caroline Glendinning, National Primary Care Research and Development Centre

Research costs money, but it also saves money in so far as it contributes to a judgement about what is most effective and produces the desired outcomes for patients in a cost effective way. Participants at all the workshops stressed the need for research into primary care and for funds to be made available for such research. Most people also saw the costs of research as part of the costs that were intrinsic to starting up a new project, though the reality seemed to be that those involved in innovation also had to find a way of resources stretching to research and development.

Training and support of researchers

Many people who are conducting research into primary care are not primarily engaged as researchers. Rather, they are professional health care workers with research skills. There is a need to support all those who are engaged in research into primary care in order to ensure a high quality of research and to develop the research skills of individuals. Research networks may be important to support researchers working across different parts of the service, and networks may also play a part in co-ordination of research initiatives.

User-centred research

In one sense, it is a truism to state that research into primary care should be user-centred, since primary care should be about the development of services in or near people's homes that are beneficial to users. However, in another sense it is necessary to stress the need for users to be central to the research agenda, for a number of reasons:

- users' views on outcomes need to be incorporated more fully
- users may have preferences for particular approaches within primary care
- different groups of users may have different views, reflecting age, gender, ethnicity, etc.
- there may be a difference of opinion between users and professionals on what is appropriate and responsive in primary care
- there may be a conflict between user-defined needs and the cost pressures on existing NHS budgets.

Dissemination of research

Further progress could be made on disseminating research results across the country, and between professional groups. Given cost pressures and the pressures on time, a greater sharing and dissemination of research findings, and a trust in work conducted by others might reduce the need to undertake research that may duplicate similar work that has been undertaken elsewhere.

Quality monitoring and performance management

One of the strengths of primary care is its diversity and its sensitivity to local need. That strength also poses problems in relation to monitoring quality. However, if primary care is to develop fully and to avoid some of the pitfalls recognised in the Listening Exercise such as variation in standards and possible inequity, it must be subject to a consistent framework of quality monitoring and performance management.

Geoff Meads, who at the time of the conferences was Regional Director of Performance Management in South and West Region, spoke of the need to have total resource management at local level, with performance management around the total resource.

AN EXAMPLE OF AN AREA WHERE STANDARDS ARE REQUIRED: THE NEED FOR STANDARDS FOR RACIAL EQUALITY

- To improve the effectiveness of agency policies
- To tailor policies to specific needs
- To improve policies through monitoring, evaluation and review
- To focus policies on race equality
- To develop the potential of staff to contribute to the success of race equality policies.

Source: Judi Linney, Health Promotion Service, West Surrey Health Authority

Chapter 4

Making primary care more responsive

The value of the primary health care team in providing ongoing support

Although primary care is sometimes viewed simplistically as the front line of care, providing the first port of call for people who may need to be referred onwards, the reality is much more complex. For some people, the real benefits of primary care lie in its ability to provide ongoing care and support. Indeed, for many people, continuity of care from a service that was geared to a holistic approach and not to a 'quick fix' is the most tangible benefit of a primary care-led NHS.

HOW THE PRIMARY HEALTH CARE TEAM CAN SUPPORT FAMILIES OF YOUNG PEOPLE WHO HAVE COMMITTED SUICIDE

- The support needed by the families of young people who have committed suicide is ongoing and may last for many years
- The expertise that the primary health care team have, and the continuity of care that they can offer can bring great support to families
- This support is unlikely to be forthcoming from specialist services over the long term

Source: Dr John Coleman, Director of the Trust for the Study of Adolescence

THE ROLE OF PRIMARY CARE IN IMPROVING THE QUALITY OF LIFE FOR ADOLESCENTS WITH LEARNING DISABILITIES

- Information on rights, services and support, communicated through pictures and symbols if the young person has difficulty in understanding primary care staff
- Education on sexuality, personal hygiene, planning for the future, etc.
- Benefits and awareness of what is available
- Diagnostic, including genetic counselling, referral to specialist supports
- Prevention, e.g. immunisation
- Counselling for young people and family; helping parents to see their son/daughter as a teenager rather than a child
- Inter-agency work to improve opportunities for training and employment
- Being vigilant about health needs of adolescents who cannot communicate through regular contact

Source: Barbara McIntosh, Project Manager for Day Services Design, King's Fund Development Centre

Users

Those who use services may have different perspectives from those who work in them. The different focus is often recognised and acknowledged by health care professionals and managers when they are themselves users.

Some aspects of user perspectives have already been noted, for example in the sections on rising demand and expectations and in the section on communication and information. However, it remains to emphasise the need for users to be at the very centre of primary care.

PRIMARY CARE AND A USER-CENTRED APPROACH

Responsiveness

The responsiveness of services is important and at MIND we still hear from users who are not treated with respect or sensitivity. A MIND survey, undertaken with the Roehampton Institute in 1991, found that 60% of people found their GP helpful. We still hear of people who cannot register with a GP because of previous mental health problems. But a positive relationship between an emotionally distressed person and primary care workers – usually a GP – is very important. Some of the ingredients of that successful relationship are:

- respect – which can engender trust
- active listening
- time – not too much, but not too little.

Service users sometimes say that GPs view them only in terms of their mental health problems, and their physical problems may not be taken seriously. Lack of time is an issue, and this is acknowledged by the BMA, who responded to a MIND paper by saying:

'It is very difficult to deal with a recognised mental illness, let alone create an environment where patients can open up about serious problems such as sexual abuse within the framework of a 10-minute consultation.'

Listening and being heard

Being listened to is important, and that has to include in the user's own language, so interpreters and translated materials are important. Primary care workers also have to be aware of different cultural needs and avoid stereotyping. This may be a training issue as well as one of workforce composition. In a study of family services conducted in Tower Hamlets, and written up in the *Bulletin of the Royal College of Psychiatrists,* 44% of GPs thought that their training in psychiatry was 'bad' or 'very bad'. Training must include everyone, not just medical staff. For example, receptionists are also important.

cont.

There is an important role for current and former users in delivering training. This can not only provide valuable insights into how services can better meet needs and expectations, but also chip away at some of the stereotypes representing people with mental health problems. The most damaging of these is the 'mad, bad and dangerous to know' stereotype. Although we are not complacent about tragic acts, in fact, there has been no increase in the incidence of homicide by people with mental health problems over the past 30 years.

Responsiveness has to include an understanding of the context within which the care worker and user/patient relationship is taking place. While the practitioner cannot take responsibility or change someone's housing conditions or isolation, it is a start just to be aware of such circumstances. To know the area and its facilities, statutory and voluntary, well enough to give helpful signposts to other services is the next step.

Information

For nearly 30 years MIND has demanded that professionals should tell clearly in plain language what is being proposed or prescribed, why, how it is likely to work and what the possible side-effects are. We have grown up in a climate of 'doctor knows best', but the tide has turned and we now talk of patient-centred services, patient power and patient's' charters. This has taken longer to reach mental health services than the world of physical ailments. MIND's survey in 1991 found that 41% of a sample of 500 ex-psychiatric patients were dissatisfied with information given about treatment by their GP.

In 1995, we launched MIND's Yellow Card Scheme for people to use to report adverse effects of treatment. The first batch of about 600 has been analysed. 87% of respondents believed that they did not receive enough information; 86% said that they were not warned of possible side-effects; 54% said their doctor was unhelpful, while 40% said their doctor was helpful. The perception of the doctor's role is not linked to whether the patient perceives the medication as helpful. These figures do not yet distinguish between primary care and hospital-based doctors.

In addition to verbal information, written information is needed to outline in a straightforward way the risks and benefits of treatments such as anti-depressants and minor tranquillisers. MIND publishes such leaflets and some are translated into community languages.

Choice

This starts with choice of GP. Many patients are not aware of their right to change GP. It is also important to have a choice of services, which could perhaps be encouraged by a primary care-led NHS and fundholding GPs. Our past research has shown that patient/user satisfaction is higher for talking treatments such as counselling or psychotherapy than for physical treatments. MIND has argued strongly for counselling and now over a third of practices have counselling available, though not necessarily on the premises. GP fundholders can clearly purchase such services and presumably could do so in collaboration with other practices to meet the needs of a wider area.

cont.

The value of counselling and therapy seems to be questioned by some people, sometimes for reasons of effectiveness, and sometimes as it is seen as diverting resources from severely mentally ill people. MIND argues that talking treatments can be valued and valuable to those who have long-term mental health problems. Also, the choice should not be either talking treatments or medication, but possibly both. In addition, the role of primary care in mental health promotion should not be underestimated, and counselling has a clear role in that.

People would also like to have an opportunity to choose within a range of services that includes befriending, self-help, traditional and complementary medicines. The Marylebone Health Centre offers these options as well as massage and stress management classes, and as a result they have been able to reduce their psychotropic drugs budget. It is not just a question of the amount of resources, but also how they are used. In a GP practice in Kent, therapies such as massage, aromatherapy, art therapy and therapeutic gardening are offered 'on prescription'. Even if such options are not offered by the primary care team, there needs to be comprehensive information about other options. For example, GPs in an area of Waltham Forest refer Asian women to a project set up and run by Asian women.

Source: Judi Clements, National Director, MIND

It is also very important to recognise both the needs and contribution of users as a groups as well as recognising the centrality of individual users.

For example, MIND has a network of service users, called Mindlink, which is central to its core values and beliefs. Mindlink was started in the mid-1980s and now has about 1500 members.

Users can also have a central role in service planning. Their participation in planning can make services more appropriate, and can remind professionals of the need to transcend organisational boundaries. Also, the involvement of users increases the need for professionals to be accountable to the people they serve.

THE ROLE OF COMMUNITY HEALTH COUNCILS IN INVOLVING USERS IN SERVICE PLANNING: AN ILLUSTRATION FROM CAMDEN

Healthlink was set up by the Camden CHCs to enable housebound people to take part in planning needs-based, effective services as required by the new commissioning function set in place by the NHS and Community Care Act. Drawing on the values of the World Health Organization's Healthy Cities Project, of which Camden is a member, stress is put on equity, public participation, multi-agency working and shifting the priorities to primary care.

Healthlink aims to support those who find it difficult to get out and about in forming a stakeholder network so that their expertise can feed into planning health and social care. The organisation has a joint funded worker, and there are now 170+ members, mostly with disabilities and mostly over 75.

cont.

The process to establish Healthlink began in 1992. To get it off the ground, leaflets were distributed by Meals-on-Wheels and home library staff, home helps, district nurses, GPs and community workers. The leaflet asked people to say what 3 main health problems they faced. Replies gave pride of place to housing problems, such as repairs, home helps, air and noise pollution, day centres and transport. This confirms primary care workers know: that many of people's worries about health are also about local authority services, including social care.

These concerns have persisted as members have taken part in consultations on discharge planning and community care planning. Users think that their opinion should be taken into account in judging the performance of individual workers who come into their home, and they want job descriptions of care staff. Procedures for assessments are seen as mechanical, not taking into account the daily variability in conditions such as multiple sclerosis. Assumptions about the availability of help from families sometimes flew in the face of strained relationships. Worries about charges have been prominent.

Members have concerns about the NHS too. Healthlink carried out its own survey on experience of using the GP, *Making the most of 10 minutes*, in 1993. They hoped that they and GPs would be able to build a consensus on how best to use services. On the whole, members were positive about their care, especially mentioning the importance of:

- efficiency
- being friendly, welcoming
- listening to the patient
- good receptionist
- being seen promptly
- nearby surgery
- nurse on premises.

Members also mentioned what worried them on visiting the GP:

- problems of physical access, especially for wheelchairs; lack of community transport; no disabled parking places; steps; waiting rooms too small
- telephone interruptions during consultation
- long waits, even with appointment
- uncomfortable chairs (low, hard) for 'walking disabled' people, e.g. with severe arthritis
- noisy waiting room (loud ventilation, uncontrolled children)
- rushed consultation
- catching up with notes on previous patients
- poor hygiene
- lack of privacy in reception area
- no access to woman health worker
- having to go to a member of practice in whom user has no confidence.

Users may not know what 'independent contractor status' means but Healthlink members do know that GPs have power that other primary care workers do not: to accept or remove a patient from the list. In recent contact with primary care commissioning staff, members have expressed real fear that the patient has to make the relationship with the GP work or face

cont.

problems of access in future. Users may be too ill, or feel too vulnerable to fight for rights when the GP, unlike other health and social care workers, has so much power.

CHCs still do not have statutory rights with respect to individual GPs. The powers of health authorities are weak. Present arrangements to hold GPs to account do not set members' minds at rest. The experience of Healthlink shows that CHCs need to have statutory rights with respect to general practice and social care and that a primary care-led NHS should have a strengthened system for accountability for general practice.

Source: Eileen O' Keefe, Senior Lecturer in Health Studies at the University of North London.

This presentation serves as a reminder that user views tend to be focused on need, while the administrative boundaries between health and social care services may be far from the core of what they are concerned about. Though users are unlikely to use this particular piece of NHS jargon, what they need is indeed what professionals refer to as 'seamless care'.

The workshop on primary care and vulnerable adolescents raised some interesting issues about the needs and views of young people as users of services.

WHAT DO ADOLESCENTS LIKE AND DISLIKE ABOUT PRIMARY CARE SERVICES?

- They do not like quiet stuffy waiting rooms, and this is not a simple matter as their preferences for music etc. may not match those of other users. But their other dislikes are similar to those of others, e.g. too long a wait to see the doctor, too short a consultation time, doctors not listening properly.

- They do value confidentiality greatly, and most adolescents do not know that it is confidential when they see the doctor. Many would like to phone the practice for advice without giving their name.

Source: Dr Ann McPherson, GP

Dr McPherson also raised some possible priorities for change if primary care is to be more attuned to its young users, including:

- Has the primary health care team ever discussed the services they provide for adolescents? Simply talking about it will produce change.
- What are the attitudes in the practice? Role-play for the whole primary health care team, including receptionists, may be useful.
- Practice profiles may highlight issues relevant to teenagers.
- Does the practice let young people know that general practice is a confidential service?
- Consideration and evaluation of routine clinics for 16 and 17 year olds
- Better information through general leaflets, practice leaflets, etc.

There is no shortage of advice on techniques to involve users of all ages. The key to success in doing so lies in attitudes and a willingness to share power. That requires a fundamental shift away from traditional attempts at user involvement, which have tended to be focused on either consultation on a narrow range of options, or surveys of satisfaction with services, or an 'educational' approach to try to encourage users to alter their patterns of service use.

Carers

The needs of carers are sometimes similar and sometimes dissimilar to those of users of services. Several presentations explicitly recognised this, and one workshop presentation in particular focused on the specific needs of carers.

ADMIRAL NURSES – SPECIALIST COMMUNITY SUPPORT FOR CARERS OF PEOPLE WITH DEMENTIA

Admiral nurses are specialist nurses working in the community as part of the NHS. They engage in casework with carers and people with dementia, making assessments, facilitating service provision and advocacy and offering emotional support. They also provide a consultancy role for other professionals, and offer casework support, education and training. Their focus is on the carer as client, and they can continue to work with a carer after bereavement. Their preventive support role has health gain benefits for carers who may themselves be frail elderly people.

The original pilot project ran for 3 years from 1989 in NE Westminster, and was extended for a further three years. Three other health authorities were offered pump priming funding for a further four schemes. In 1994, the Dementia Relief Trust was set up to develop the service and raise funds for further support.

Key questions are:
- how effectively are the health needs of carers and families addressed in current patterns of primary care and referral?
- how can the admiral nurse model assist and complement the development of a primary care-led NHS?
- how can admiral nurses and primary care practitioners liaise effectively to improve outcomes and standards of care?

Source: Huw Meredith, Development Director, Dementia Relief Trust, and Debbie Williams, Admiral Nurse, Riverside Mental Health NHS Trust

A number of themes relating to carers recurred throughout the workshops, for example:

- What support is available to carers?
- Are the distinctive needs of the carer recognised?
- How are carers' views taken into account in developing services?
- How are changes in society impacting on the availability of carers?

- The extreme age and vulnerability of many carers.
- The specific needs of children and young people who are carers.

Unless these issues are addressed, primary care and care in the community will be seen by many as a liability rather than an improvement in the lives of carers and those for whom they care.

Voluntary organisations

The part played by voluntary organisations in primary care is complex. The following roles were identified:

- providers of services
- advocates for individual users and carers
- campaigners for service improvements and developments
- sources of information to users and carers
- conduits for information from users and carers.

Voluntary organisations have played a historic role in supporting and delivering care to people with disabilities and chronic illnesses – the aspects of health care on which primary care is particularly focused, and from which acute hospital services have tended to shy away.

Diane Plamping reminded workshop participants that policy-makers in all the industrial and post-industrial world are faced with a gap between life expectancy and age of onset of disability. And they all inherit health services which were not originally designed to take chronic ill health as seriously as acute disease management and have even less a tradition of treating patients as experts.

Eileen O'Keefe spoke of the important part played by CHCs in involving voluntary organisations in health issues. Many CHCs took it to be their task to become facilitators for voluntary organisations and community groups on their patch. Instead of just responding to consultation, they felt they had to be involved in and facilitate a dialogue with commissioners. This would give greater voice to Black and ethnic minority, disabled, low income, lesbian and gay groups in commissioning.

The contribution made by the voluntary sector in promoting information to users about services was mentioned several times. One participant who came from a voluntary organisation pointed out that professionals should work with the voluntary sector to improve information to local people about their rights to local services. This applied in particular to older people, who sometimes tended to feel that they should not ask for help, or may not be aware what help was available.

One workshop at the event on primary care and frail elderly people looked specifically at a view from the voluntary sector:

SUPPORT FOR FRAIL ELDERLY PEOPLE AND CARERS: A VIEW FROM THE VOLUNTARY SECTOR

- Effective communications are needed; IT developments are important – e.g. the directories of Councils for Voluntary Service could be put on disk
- Co-ordination and partnerships are essential – we need to explore how to work together in partnerships
- The voluntary sector is an advocate with and for users and fulfils a bridge-building role, but funding is needed for this role.
- Small voluntary organisations, especially Black and ethnic minority organisations, still do not have a way in to planning.
- The voluntary sector is also a provider, and needs to work on how to fulfil that role as well as being advocates, lobbyists etc. The voluntary sector also needs to be invited to meetings in its provider capacity.
- The voluntary sector is not the same as users, and older people themselves ought to be communicated with directly.
- Older people should be involved in defining outcomes
- Primary care for frail elderly people cannot succeed unless it is complemented by good social care
- A multi-disciplinary approach should include older people alongside professionals

Source: Paula Jones, Director, Age Concern, London

Issues of funding loom large for the voluntary sector, and small voluntary organisations often have to spend a disproportionate amount of time fund-raising. Where they are funded by a range of sources, the process of application and monitoring can take more time than the fulfilment of the voluntary organisation's core business.

Hilary Scott, Chief Executive of Tower Hamlets Community Trust, who chaired the conference on primary care and frail elderly people, asked this important question: how can voluntary organisations be developed in the context of the contract culture, without over-bureaucratising them?

If the NHS and social care agencies are to benefit from the continued involvement of the voluntary sector (and it is hard to see how they could survive without it), more secure and predictable ways of funding voluntary organisations must be found and whatever ways are explored must also allow voluntary organisations to retain their distinctive identities.

Appendix
Programmes

What Makes Change Happen in Primary Care?

A Conference for Managers and Practitioners
Friday, 14 June 1996, 10–4pm

Chair: Ms Christine Beasley, Regional Director of Nursing, NHS Executive,
North Thames Regional Office

Morning session: Key issues in primary care

10.00–10.10	Introduction and welcome
10.10–10.50	*What are the qualities of primary care?* Diane Plamping, Fellow in Primary Care, King's Fund
10.50–11.10	*Coffee*
11.10–1.00	Key issues in primary care – themes from the Radcliffe series of books *From invention to innovation,* June Huntington, Independent Consultant in health care management and Visiting Fellow of the King's Fund. *The practice of the 21st century* – Geoff Meads, Regional Director of Performance Management, NHS Executive, South and West Regional Office. *Developing Primary Care Resource Centres in the North West of England* – Caroline Glendinning, National Primary Care Research and Development Centre, University of Manchester.
1.00–2.00	*Lunch*

Afternoon session: Making change happen

2.00–2.45	*Users in multi agency planning* Eileen O'Keefe, Senior Lecturer in Health Studies, University of North London
2.45–3.30	*What makes change happen in primary care?* Tim van Zwanenberg Director of Health Commissioning and Primary Care Development, Newcastle and North Tyneside Health Authority
3.30–4.00	Panel discussion: closing remarks

Primary Care and Frail Elderly People

A Workshop for Managers and Practitioners
Friday, 6 September 1996, 9.45am–4pm

Chair: Hilary Scott, Chief Executive, Tower Hamlets Health Care Trust

09.45–10.15	*Coffee and Registration*
10.15–11.00	*Support Not Crisis* – Dr Jackie Morris, Consultant Physician in Medicine of Old Age, Royal Free Hospital
11.00–11.30	*The role of nursing in primary care for frail elders* – Jo Hesketh, Director of Nursing and Quality, Shropshire Community Health Services NHS Trust
11.30–11.50	*Coffee*
11.50–12.20	*Purchasing and providing services for frail elders* – Dr Michael Gocman, GP and Chair of New River Total Care Project and Dr Chris Jephcott, White Lodge Group Practice, Enfield
12.20–1.15	*Avoiding hospital admission for elderly people (includes purchaser and provider perspectives on a Hospital-at-Home Scheme)* – Helen Fentimen, Director of Primary Care and Community Care, Redbridge and Waltham Forest Health Authority; Michele Sappa, Director of Primary Care, Forest Healthcare Trust
1.15–2.15	*Lunch*
2.15–3.15	WORKSHOPS: a) Lessons from the work of the London Health Partnership – Martin Fischer b) Admiral nurses – specialist community support for carers of people with dementia – Huw Meredith, Dementia Relief Trust and Debbie Williams, Admiral Nurse c) Support for frail elders and carers: a view from the voluntary sector – Paula Jones, Director of Age Concern London
3.15–4.00	Plenary feedback and concluding remarks
4.00	*Tea*

Primary Care and Mental Health

A Workshop for Managers and Practitioners
Monday, 9 September 1996, 9.45am–4pm

Chair: Elaine Best, Regional Mental Health Co-ordinator, NHS Executive,
North Thames Regional Office

09.45-10.15	*Coffee and Registration*
10.15-10.20	Chair's welcome
10.20.10.55	*Mental health and primary care* – an overview by Dr Sheila Adam, Head of Mental Health and NHS Community Care, Department of Health
10.55-11.30	*Effective commissioning for primary mental health care* – Susan Williams, Joint Chief Executive, Barking & Havering Health Authority
11.30-11.50	*Coffee*
11.50-12.20	*Influencing mental health service provision through total fundholding* – Dr Rod Smith GP
12.20-12.50	*Primary care and mental health – whose needs are being met?* – Judi Clements, National Director, MIND
12.50-1.15	Questions to speakers and discussion
1.15-2.15	*Lunch*
2.15-3.15	WORKSHOPS: a) Housing and mental health – Julie Webb, Circle 33 Housing Association b) Counselling in primary care-is it worth it? – Helen Allen, Dorset Research and development Unit, Bournemouth University c) The role of GPs – Dr Alan Cohen, Visiting Fellow, King's Fund, General Practitioner, London
3.15-4.00	Plenary feedback and concluding remarks
4.00	*Tea*

Primary Care and Vulnerable Adolescents

A Workshop for Managers and Practitioners
Monday, 21 October 1996, 9.45am–4pm

Chair: Judy Hargadon, Director, Primary Care Support Force

09.45–10.15	*Coffee and Registration*
10.15–10.20	Chair's welcome
10.20–10.50	*The Health of the Young Nation* – an overview by Dr Kathie Binysh, Senior Medical Officer, Department of Health
10.50–11.30	*Growing up with chronic illness* – the role of primary care – Dr Zarrina Kurtz, Consultant in Public Health and Health Policy
11.30–11.50	*Coffee*
11.50–12.20	*Are adolescents getting a fair deal from general practice?* – Dr Ann McPherson, GP and author of *Diary of a Teenage Health Freak*
12.20–12.50	*Adolescent suicide and self harm – the role of primary care –* Dr John Coleman, Trust for the Study of Adolescence
12.50–1.15	Questions to speakers and discussion
1.15–2.15	*Lunch*
2.15–3.15	WORKSHOPS: a) Adolescents with learning disabilities -Barbara McIntosh, Project Manager, Day Services Design (Learning Difficulties), King's Fund b) Innovative approaches in working with adolescents – David Tait, Base 51, Nottingham c) Primary care for vulnerable adolescents from Black and ethnic communities – Judi Linney, Head of Health Promotion, West Surrey, and Vice President of Woking Community Relations Forum
3.15–4.00	Plenary feedback and concluding remarks
4.00	*Tea*

Primary Care at 3am – Emergency and Out-of-Hours Care

A Workshop for Managers and Practitioners

Friday, 25 October 1996, 9.45am–4pm

Chair: Judie Yung, Regional Director of Purchaser Performance Management,
NHS Executive, North Thames Regional Office

09.45–10.15	*Coffee and Registration*
10.15–10.20	Chair's introduction
10.15–11.00	*Primary care at 3am* – an overview – Lesley Hallam, Research Fellow, National Primary Care Research and Development Centre, University of Manchester
11.00–11.30	*The contribution of nursing to out-of-hours care* – Alison Norman, Executive Director of Nursing and Primary Care, North Staffordshire Combined Healthcare NHS Trust
11.30–11.50	*Coffee*
11.50–12.20	*Nurse telephone triage* – Val Lattimer, Senior Research Fellow, Wessex Institute of Public Health Medicine
12.20–12.50	*Where do GP co-operatives fit in?* Dr Mark Reynolds, GP and Secretary of the National Association of GP co-operatives
12.50–1.15	*The role of A & E in out-of-hours care* – Dr Stephen Miles, Consultant in A & E, Royal London Hospital, and immediate past Secretary of the British Association of A & E medicine
1.15–2.15	*Lunch*
2.15–3.15	WORKSHOPS: a) Ambulance services and out-of-hours care – Laurie Caple, Northumbria Ambulance Service NHS Trust b) GP co-ops (continued) – Dr Mark Reynolds (as above) c) A & E in out-of-hours care (continued) – Dr Stephen Miles (as above)
3.15–4.00	Plenary feedback and concluding remarks
4.00	*Tea*