



Improving quality and safety: progress in implementing clinical governance in primary care

Patients, carers and voluntary organisations

Final report

January 2006

Prepared for the National Audit Office by:

Pilgrim Projects Limited

91 Waterbeach Road

Landbeach

Cambridge CB4 8EA

Tel: 01223 440257

Fax: 01223 863826

www.pilgrimprojects.co.uk

© National Audit Office 2007

CONTENTS

Introduction	3
Methodology/engagement	4
Overview	13
Key findings	15
Good practice case studies	55
Overall lessons	58
Appendix 1	60

INTRODUCTION

‘Clinical governance defines the values, the culture, the processes and procedures that must be put in place in order to achieve sustained “quality of care” both within and between the organisations that make up the NHS.’

The Strategic Leadership of Clinical Governance (2003)

The NAO’s objective in conducting a large scale VFM investigation was to evaluate the success of Clinical Governance in primary care in helping to improve the quality of the delivery of care. In the past few years, the Government has continued to stress that Clinical Governance and patient safety and the patient experience are at the heart of its plans. There is an issue, therefore, about the extent to which Primary Care Trusts, with the range of initiatives they are managing, are translating these national aims into the tangible delivery of service improvements locally. The question we have sought to answer is, therefore:

Are PCTs achieving improvements in the patient experience and quality of care delivered to patients?

Through direct engagement with voluntary organisations representing patient and carer groups, our research examines what more needs to be done for patient and carer involvement in service delivery to be effective. Through qualitative research groups and questionnaires, we provide examples of patient experiences, and an indication of performance so far.

METHODOLOGY/ENGAGEMENT

Our methodology has consisted of three main strands:

- survey of patient and carer groups/voluntary organisations
- review of existing research already carried out by these organisations
- direct engagement with patients and carers.

Survey of patient and carer voluntary organisations

We have engaged with 15 voluntary organisations (listed below and in Appendix 1) at national and regional level. CEOs of each organisation received a questionnaire to complete. Some CEOs disseminated the questionnaire to regional managers. Fourteen questionnaires were returned, although five of these have come from Diabetes UK regional offices; thus ten organisations are represented by completed questionnaires. We have had telephone conversations with representatives from two organisations who felt unable to complete the questionnaire. Follow-up phone calls were also offered to all other CEOs; three other organisations engaged with us in this way through their CEO or another official.

Existing research

All organisations were asked to provide us with the results of any research they had carried out to assess the quality of care received by members.

The following organisations have sent us research reports or articles:

- Carers UK
- Princess Royal Trust for Carers
- Lindsay Leg Club Foundation
- Cystic Fibrosis Foundation
- National Endometriosis Society.

In addition, research material was available via the Asthma UK website. We have also drawn on previous research carried out with patients and carers and also carried out some research on the Internet in relation to those organisations we surveyed. We have also made use of a report of Black and Minority Ethnic (BME) Needs Assessment for hypertension and diabetes, produced by Lewisham Community Development Partnership.

Direct engagement with patients and carers

The second main strand of our research involved attending local meetings of these patient and carer organisations. In the environment of their regular group meetings, we have listened to patients' and carers' experiences of healthcare. Open communication was facilitated by small group sizes, and familiarity with the context.

A donation was made by Pilgrim Projects to each of the groups we visited.

Additional research/engagement

In addition, we have:

- convened and worked closely with The Carers Friday Club to organise a conference for carers, jointly with the Clinical Governance Support Team and the Princess Royal Trust for Carers
- attended the 'Quality Dashboard' conference/workshop for patients and carers organised by the Clinical Governance Support Team
- engaged in email correspondence with three people who have Cystic Fibrosis, and who are unable to attend members' meetings due to the risk of cross infection
- spoken with two patients with Chronic Fatigue Syndrome
- spoken with CEOs of the MPS Society and Cintra, and Age Concern's Head of Policy
- visited the Kilburn African Caribbean Elders' Centre
- visited the Carers' Resource Centre in Harrogate
- followed a thread on a newsgroup relating to access/patient care.

We have spoken in depth with people representing the following groups:

- Endometriosis (three groups in different parts of the country)
- Blood Pressure
- Alzheimers
- Leg ulcers (two groups in East Anglia)
- African Caribbean Elders
- Carers (for people with a wide range of conditions)
- A mixed group of patients and carers attending an event organised by the CGST.

We have also drawn on earlier work with patients and carers through the Engaging Carers conference (2004) and the Patient Voices programme. This is a growing collection of digital patients' and carers' stories, initially funded by the Clinical Governance Support Team for use with Board teams and for use in e-learning programmes, to ensure a patient focus in healthcare education.

Summary of organisations and conditions included in our investigation

'Primary Care Trusts provide a wide range of services to help alleviate many chronic and long-term conditions such as diabetes, dementia, stroke and back pain. Services are provided through many diverse professional groups, including General Practitioners, practice nurses, physiotherapists, pharmacists, dentists, optometrists and ophthalmologists. Provision of primary care to patients, particularly for long-term care, will also require linkages with many social care organisations. Chronic ill health – long standing sickness, disability or infirmity - affects 35 per cent of the population overall, and almost three quarters of those aged over 75.'

NAO (2005) Business Case: Primary care clinical governance

Table 1 offers a summary of the conditions we have investigated, the numbers of people who are affected, the kinds of primary care that might be necessary and the voluntary groups that can offer support.

Table 1 Examples of some long-term conditions, the type of care that may be required and supporting voluntary organisations

Condition and numbers affected	Examples of primary care	Supporting organisation
<p><i>African and Caribbean Elders</i></p> <p>The 1991 Census indicated that the African-Caribbean community was the second largest minority ethnic group in Britain. It is estimated that Blacks (of African origin regardless of place of birth) and Caribbeans over 65 years of age constitute a quarter of the British population in that age group (Source: Labour Force Survey, 1999-000 Office for National Statistics).</p> <p>BME communities are likely to see higher incidences of hypertension and diabetes, and some other conditions that are more likely to affect people of African and Caribbean heritage.</p>	<p>Medical diagnoses may be based on prejudice, cultural differences and stereotypical assumptions (eg myths of extended family support networks and 'Black and dangerous').</p> <p>Black elders are susceptible to all the problems associated with old age and, in addition, may face prejudice and misunderstanding. Services based on a Eurocentric perspective of caring may be at odds with their own culture and lifestyle.</p> <p>(See www.mind.org.uk Factsheet on Diversity).</p> <p>They require tailored advocacy services, health promotion, exercise and social activities across health, education and social care. All members of our multi-cultural society deserve respect and compassion, open communication and an attempt to understand their cultural perspective before assumptions are made.</p>	<p>The African and Caribbean Elders Luncheon Club & Community Support Centre is a Camden Net Community Group in the London Borough of Camden. They serve a pro-rata proportion of the 58 % of 'Black' Caribbeans, and 44 % of Other Black people who live in Greater London*). They receive advocacy, health promotion, exercise and social activities as well as computer training for free at the centre; additional support is provided for housebound elders and for their careers at home and in hospital.</p> <p>(*16 per cent of 'Black' Caribbean people live in the West Midlands. Source = 1991 Census)</p>
<p><i>An Ageing Population</i></p> <p>The number of people over pensionable age, taking account of the change in the women's retirement age, is projected to increase from nearly 11.4 million in 2006 to 12.2 million in 2011, and will rise to nearly 13.9 million by 2026, reaching over 15.2 million in 2031. (GB) In 2002, 63% of people aged 65-74 and 72% of people aged 75 and over in the GHS sample reported a longstanding illness.</p> <p>Of those aged between 65 and 74, 41% and, of those aged 75 and over, 53% said that they had a limiting longstanding illness. (Source: Facts, Figures and Research. Older People in the United Kingdom - General Statistics 2004, An Ageing Population, Age Concern, England)</p>	<p>Examples of primary care services, in collaboration with Age Concern England, include: Energy Advice Projects; Footcare and Nailcutting Schemes; Healthy Ageing: Activities to promote good health in later life; Post-hospital Care for Older People; Setting up and Running a Hospital Aftercare Service; 'So much more than just walking'.</p> <p>Elderly people are more likely to have complex medical needs, and the quality of life needs to be considered when planning treatment; this requires effective working across health and social care teams.</p>	<p>Age Concern provides services for men and women over 55; support services for carers of people with dementia; advocacy services for people in care homes; services making regular telephone calls to housebound or isolated clients; hospital aftercare services; and learning and leisure.</p> <p>www.ageconcern.org.uk</p>

Condition and numbers affected	Examples of primary care	Supporting organisation
<p><i>Alzheimers Disease and Dementia</i></p> <p>Alzheimer's disease is a progressive form of pre-senile dementia that is similar to senile dementia except that it usually starts in the 40s or 50s; first symptoms are impaired memory, which is followed by impaired thought and speech and finally complete helplessness (http://wordnet.princeton.edu/perl/webwn)</p> <p>Around 600,000 people in the UK* have dementia, and more than half of these have Alzheimer's disease. Dementia affects one in 20 people over the age of 65 and one in five over the age of 80. Source: Making connections - new partnership means better care for people with dementia, Department of Health press release, July 2002, ref 2002/0314</p> <p>*The Alzheimer's Society however estimates that there are currently over 750,000 people in the UK with dementia, of which only 18,000 are aged under 65.</p>	<p>Primary Care Trusts and social services work in partnership to provide information, guidance and support. For example specialist home teams, supported by community psychiatric nurses and specialist occupational therapists, to help people with dementia live in their own homes.(Source: NAO Business case) .</p> <p>The Alzheimers Society provides helplines, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It also campaigns for improved health and social services and greater public understanding of all aspects of dementia</p>	<p>The Alzheimers Society provides expertise, information and support for people with dementia, their families and the professionals who work with them and to work in partnership with other organisations that share its aims.</p> <p>The Society has over 25,000 members and operates through a partnership between over 250 branches and support groups and the national organisation in England, Wales and Northern Ireland. It was founded in 1979 as the Alzheimer's Disease Society.</p> <p>www.alzheimers.org.uk</p>
<p><i>Asthma</i> is a common condition that affects the airways (bronchi) of the lungs. From time to time the airways constrict (become narrow) in people who have asthma.</p> <p>Asthma cannot be 'cured', but treatment is usually effective. 5.2 million people in the UK suffer from asthma...including 1.1m children. One household in five has at least one person with asthma.</p> <p>Asthma is costing the UK more than £2.3 billion a year through the NHS, benefits and lost working days. 'The UK has one of the highest rates of people with asthma of any country in the world,' said Asthma UK's Chief Executive, Donna Covey. (Source: www.asthma.org.uk Report "Where do we Stand?" (published Dec 2005) in assoc with the Lung and Asthma Information Agency).</p>	<p>The report 'Where do we Stand?' (see previous column) suggests that, since the cost of treating an asthma attack in hospital is 3.5 times that of treating well-controlled asthma, it would make more financial sense to invest in primary care programmes to help people with asthma control their symptoms.</p> <p>According to Asthma UK "In order to improve care for people with asthma, we need to work in partnership with health professionals. Programmes would include developing guidelines, information, healthy living, etc.'</p>	<p>Asthma UK keeps detailed statistics about asthma in the UK, which are not otherwise widely available, thus filling a gap. They also run events, such as National Conferences with the National Respiratory Training Centre, publish information such as Patient Guidelines, magazines, booklets, reports and fact files and provide a forum for healthcare professionals to exchange ideas; assist with medical research and do campaigning in schools etc.</p> <p>www.asthma.org.uk</p>

Condition and numbers affected	Examples of primary care	Supporting organisation
<p><i>'Carers'</i> – or <i>'family carers'</i> look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.</p> <p>One in eight adults in the UK is a carer ... this amounts to around six million people. Over 1 million people care for more than one person. Every year, over 2 million people become carers, 3 in 5 people will become carers at some point in time.</p> <p>By 2037 the number of carers could have increased to 9 million. Over 3 million people juggle care with work). (Source: Carers UK).</p>	<p>1.25 million people provide over 50 hours of care per week; people providing high levels of care are twice as likely to be permanently sick or disabled (Carers UK). The National Strategy for Carers (<i>Caring for Carers, 1999</i>) sets out the government's intentions, stating that 'Carers have a right to expect that the NHS and social services should help them maintain their own health'.</p> <p>Recommendations to health and social care organisations: keeping local registers; publicity and awareness training for staff; systems to provide carers with information and ways to get feedback from carers – see Barclays 'Carers Speak Out Project' in collaboration with, and published by Princess Royal Trust for Carers, 2004</p>	<p>Carers UK and Princess Royal Trust for Carers are the UK voices for carers, providing publications, conferences, campaigning and awareness training to staff, and supporting carers in employment etc. They also provide support and information directly to carers through local and regional branches and carers' centres.</p> <p>www.carersuk.org/ www.carers.org</p>
<p><i>Cystic Fibrosis</i> (CF) is the UK's most common, life-threatening, inherited disease, affecting about 1 in every 2,500 white children born. It affects over 7,500 people in the UK, 50% of whom are under 15 and 70% under 20). It affects vital organs in the body, especially the lungs and digestive system, clogging them with sticky mucus, which makes it difficult to breathe and digest food.</p> <p>Average life expectancy for someone with CF is 31 years. (Source: Cystic Fibrosis Trust)</p> <p>The condition is much more rare in people of African or Asian descent. (Source: www.bupa.co.uk)</p>	<p>Health care needs to aim to ensure that people with CF receive the best possible care and support in all aspects of their lives (Cystic Fibrosis Trust). Effective multi-disciplinary teams are essential to the well-being of people with Cystic Fibrosis. Since the vast majority of those affected are children or young people, this needs to be taken into account when planning services.</p>	<p>The Cystic Fibrosis Trust funds research aimed at understanding, treating and curing Cystic Fibrosis. They also support groups in local areas.</p> <p>www.cftrust.org.uk</p>
<p><i>Diabetes</i>: 1.3 million people in England suffer from diabetes, and the number is increasing. Without proper management, diabetes can lead to long-term complications such as an increased risk of coronary heart disease and stroke, kidney failure, foot ulceration (sometimes lead to amputation), and blindness. Diabetes can have a major impact on the physical, psychological and material well-being of individuals and their families.</p>	<p>Information and education to people with diabetes self care, with support from professionals such as nurses and dieticians. Patients require dietary advice on how to control and monitor their glucose levels, blood pressure and other factors for developing complications of diabetes.</p>	<p>Diabetes UK funds research, campaigns and helps people live with the condition; aiming to improve the lives of people with diabetes while working towards a future without diabetes.</p> <p>www.diabetes.org.uk/</p>

Condition and numbers affected	Examples of primary care	Supporting organisation
<p><i>Endometriosis</i> is a condition where the cells that are normally found lining the uterus are also found in other areas of the body, usually (but not always) within the pelvis. It causes internal bleeding into the pelvis, but unlike a period, there is no way for the blood to leave the body. This leads to inflammation, pain and the formation of scar tissue. Endometriosis can be found in or on the bowel, in or on the bladder, in operation scars and in the lungs. The cause is unknown (Source National Endometriosis Society - www.endo.org.uk).</p> <p>About 2 million women in the UK are affected by endometriosis – the same number of people as are affected by Diabetes. It can develop at any age - from early teenage to the menopause – and affects all areas of life, causing great pain and suffering, as well as necessitating time away from work and education.</p>	<p>Endometriosis sufferers need from primary care a recognition which is as widely acknowledged and accepted as other chronic conditions are already. Women need to receive faster referral (research carried out by the National Endometriosis society revealed that the average time between first reporting symptoms and receiving a diagnosis was seven years in 1994 but has now increased to ten years). They also need appropriate treatment to give them every opportunity to enjoy quality of life, as well as education and training, so that this condition is no longer a 'secret' or taboo.</p>	<p>National Endometriosis Society works to see more funding of research so that the disease can begin to be understood and so that more effective treatments are found, so as to reduce the impact the disease currently has on so many lives.</p> <p>The Society also provides a range of services that offers hope, information and support for women with endometriosis, as well as partners and families. Regional groups offer regular support to members, enabling them to share experiences and benefit from sharing new knowledge.</p> <p>www.endo.org.uk</p>
<p><i>High Blood Pressure</i> (or Hypertension) occurs when blood is forced through the arteries at an increased pressure. Around 10 million people in the UK have high blood pressure - that's one in five of us. Source: www.netdoctor.co.uk</p> <p>High blood pressure increases the risk of stroke and heart disease</p>	<p>Every adult near or past middle age should 'know their numbers'- ie height, weight, blood pressure and cholesterol levels. They also need to have regular blood pressure tests if there is a family tendency for hypertension. This way, treatment can be started before any complications arise.</p> <p>Prevention is better than cure, so primary care programmes which target a change of lifestyle need to be duplicated, such as information around smoking cessation, weight loss, regular exercise, low alcohol intake, healthy eating, stress reduction and relaxation programmes. 'These changes will lower blood pressure - to reduce your risk of developing the condition in the first place or to treat hypertension.' (www.netdoctor.co.uk and the British Hypertension Society)</p>	<p>The Blood Pressure Association helps people with high blood pressure become more aware and more involved in controlling their condition. The Association provides information; an Annual national BPA blood pressure testing week - "Know Your Numbers" - every September and support groups, by people with high blood pressure for people with high blood pressure.</p> <p>www.bpassoc.org.uk</p>

Condition and numbers affected	Examples of primary care	Supporting organisation
<p><i>Language-needs support, working across language and culture</i></p> <p>Access to services and information is part of the equal opportunities policies of all social and health care organisations. Many people do not have English as their first language. Others have need of communication support because of physical, biological or mental health problems. All members of the community should have the right to equal access to effective public services.</p> <p>To deliver their services to speakers of languages other than English, and to support those with other communication support needs, providers need appropriate interpreting and translation services, rather than relying on friends or family.</p>	<p>Good communication is essential if effective healthcare services are to be provided. Patients and carers need to understand their conditions, diagnoses and options for treatment. Professional interpreters are the only way to ensure that communication is effective between healthcare professionals and the people they care for.</p> <p>All interpreters should adhere to a code of conduct of confidentiality and impartiality, quality of interpretation.</p> <p>There is a need for provision of interpretation services and communication support: over the phone; translations of brochures, leaflets reports etc; consultancy and advice and for training within public services in working with interpreters, both in social and health care with interpreters.</p> <p>Interpreters should be qualified to required professional standards and receive ongoing CPD.</p>	<p>Cintra Cambridgeshire Interpreting and Translation Service (CINTRA) offers a complete interpreting and translation service for the public services in Cambridgeshire and the East of England.</p> <p>Cintra specialises in face-to-face interpreting for public services and the voluntary sector, where the interpreter attends the appointment.</p> <p>Cintra promotes professional standards in interpreting, which are recognised to be the Diploma in Public Service Interpreting (DPSI) or NVQ Level IV for British Sign Language Interpreters and ensures ongoing CPD and support for all its interpreters.</p> <p>www.colc.co.uk/cambridge/cintra/index.htm</p>
<p><i>Leg Ulcers</i></p> <p>About 120,000 people in the UK are suffering from leg ulcers today, with 500,000 of these having recurrent leg ulcers.</p> <p>About half of these people <i>could</i> be permanently cured if they saw a specialist vascular surgeon and had specialist surgery. (Source: www.medicalpages.co.uk, written by The Specialist Vascular Consultants at The Whiteley Clinic)</p> <p>The vast majority of people with leg ulcers can be helped by education and improved self-management, such as that provided by Leg Clubs.</p>	<p>Care needed: Recognition there may be a problem. Assessment and discussion of the results with patient; surgery may be indicated (approx 60% of patients); the other 40% will be helped by long term compression. (Source: The Whiteley Clinic)</p> <p>Leg Club staff work in a unique partnership with patients (members) and the local community. Working to best-practice guidelines, they provide a high standard of care in a social and friendly setting that promotes understanding, peer support and informed choice. (Source: Lindsay Leg Club Foundation)</p>	<p>Lindsay Leg Club Foundation runs local Leg Clubs, an evidence-based initiative which provides community-based treatment, health promotion, education and ongoing care for people of all age groups who are experiencing leg-related problems.</p> <p>Leg Clubs typically meet once a week. No appointments are required and members can drop in to chat over a cup of tea or coffee while awaiting treatment. Transport can be arranged to and from the clubs, and parking is always available.</p> <p>There is growing evidence that this social model of care is reaping enormous benefits for patients and staff, with reduced incidence of recurrence and resulting complications and patients reporting less discomfort – as well as improved quality of life.</p> <p>There are now 17 Leg Clubs in the UK.</p> <p>www.legclub.org</p>

Condition and numbers affected	Examples of primary care	Supporting organisation
<p><i>Mucopolysaccharide (MPS) diseases</i> are metabolic diseases which affect one baby in every 25,000 born – that's one born every eight days in the UK. There are 21 different MPS and related diseases, including Hurler, Hunter, Sanfilippo and Morquio disease. The diseases are caused by a missing enzyme which regulates storage of waste substances in cells, including the brain and major organs and causes progressive physical and, in many cases, mental disability, usually resulting in death in childhood. There is currently no cure for MPS diseases. (Source: mpssociety.co.uk)</p>	<p>Primary Care organisations which support good practice for MPS would collaborate closely with the support networks for those affected by MPS & Related Diseases, joining them in bringing about more public awareness while supporting research into MPS & Related Diseases.</p> <p>Primary care and social services need to work together to provide care and support for the range of complex needs of MPS patients and their families, from the most basic provision of nappies through education and schooling to the need for respite and palliative care.</p>	<p>MPS Society is a voluntary support group founded in 1982, which represents over 2400 children and adults in the UK suffering from MPS, as well as those involved in their care. The Society offers support, education and advocacy, research and public awareness campaigning.</p> <p>www.mpssociety.co.uk</p>
<p><i>Osteoporosis</i> literally means 'porous bones'. Osteoporosis occurs when the holes within a bone become bigger, making it fragile and liable to break easily. Osteoporosis usually affects the whole skeleton but it most commonly causes breaks (fractures) to bone in the wrist, spine and hip.</p> <p>An estimated three million people in the UK suffer from osteoporosis</p> <p>One in two women and one in five men in the UK will suffer a fracture after the age of 50.</p> <p>Every three minutes someone has a fracture due to osteoporosis.</p> <p>Each year there are more than 230,000 fractures which include over</p> <ul style="list-style-type: none"> - 70,000 hip fractures - 50,000 wrist fractures - 120,000 spinal fractures <p>Osteoporosis costs the NHS and the government over £1.7 billion each year, that's £5 million each day.</p>	<p>Health programmes which focus on exercise; smoking cessation and education about safe intake of alcohol and a diet of good calcium intake 'throughout life for healthy bones' are recommended by Dr Dan Rutherford, GP (written for www.netdoctor.co.uk).</p> <p>In the London Borough of Camden, Walking and Dance exercise groups are sponsored for Leisure Card holders, aiming to promote the physical, social and psychological benefit of dance in the community, setting up and delivering a range of different dance classes in the borough. The dance activities and regular classes for adults are aimed at the over 50s but everyone from late 20s to 100 years of age are welcome (at £1 per class, in partnership with Camden and Islington Primary Care Trust)</p>	<p>National Osteoporosis Society has a vision of a society in which prevention, treatment and care of people with osteoporosis is of the highest standard and consistently available.</p> <p>The Society, with 49 staff and an annual turnover of £5m, undertakes research, assisted by nearly 1,000 volunteers across the United Kingdom, the majority in 130 local groups.</p> <p>They offer a helpline, working closely with professionals. They have 27,000 members, made up of people living with osteoporosis, their families, carers, clinical and research professionals.</p> <p>www.nos.org.uk</p>

OVERVIEW

Our key findings can be summarized as follows.

1 The significant value of unpaid carers and of voluntary patient and carer organisations is often unrecognised.

- Unpaid carers and voluntary organisations make a contribution to the health service that is valued in excess of £57.4¹ billion.
- Carers want to be recognised for the contribution they make.
- Voluntary patient and carer organisations are filling a gap by providing services that neither the NHS nor Social Services has the capacity to provide.

2 Voluntary organisations' ability to complement NHS services by providing patients, carers and clinicians with expertise, information and support is under-utilised and undervalued by PCTs.

- Voluntary organisations do work with PCTs to ensure that clinicians and patients have the appropriate information about specific conditions but examples of this are not widespread.
- Patient and carer groups have an appetite to work more closely with PCT working groups but as yet few PCTs engage in a consistent and co-ordinated way
- Mutual engagement between PCTs and patient/carer support groups elicits mutual benefits
- Patients, carers and voluntary organisations want clinicians to be involved in support groups

3 Patient and carer voluntary organisations display some awareness of the principles of clinical governance and its agenda, but individual patients and carers have little or no understanding of clinical governance and, on balance, report unsatisfactory experiences of primary care.

- Clinical governance makes little difference to the quality of care in practice.
- CG is often regarded as a stick to beat PCTs with
- Improvements are patchy.
- Patient groups have limited experience of clinical audit and risk assessment

¹ Based on care costs in 2000. From *Without Us...? Calculating the value of carers' support*. Copyright Carers UK 2002 www.carersonline.org.uk

- Public consultation should result in improved care
- Patients believe that targets and financial constraints are more important to the NHS than the quality of care.
- Patients identify concerns about clinical staff in relation to lack of empathy, understanding, advice and quality of care.

4 Respect, listening and communication from clinicians are essential to improving the patient experience.

- Insensitivity and ignorance among clinicians are common complaints.
- Consideration and respect engender confidence and positive views.

5 Patients want, and expect, to experience seamless, person-centred care.

- Patients have only one journey through the NHS but are conscious of a lack of joined-up thinking and working.
- Patients and carers want a truly patient-centred health service
- Patients view consultation, engagement and communication as central to improving the patient experience.
- Patients regard themselves as people first

6 Education and information for clinicians, carers and patients improves their experience.

- Education and information for clinicians is fundamental:
 - about conditions
 - about dealing with people
- Information enables patients and carers to participate more fully in the process of care.
- Support groups/voluntary organisations see their role as central in education.

KEY FINDINGS

1 The significant value of unpaid carers and of voluntary patient and carer organisations is often unrecognised.

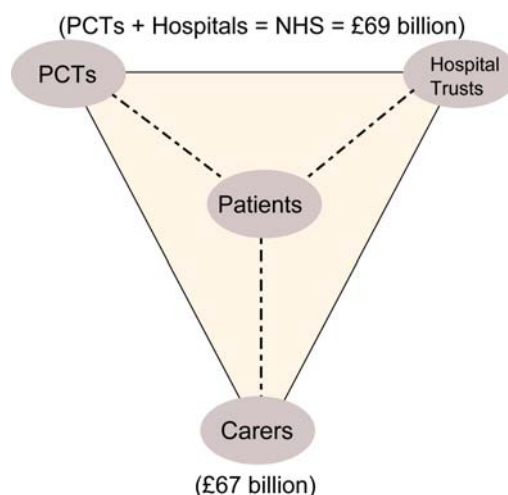
'The number of carers with heavy caring commitments is similar to the total number of employees within the NHS. Indeed, calculations of the value of the support given by carers have put it at around the same level as the total of UK spending on health.'

Princess Royal Trust for Carers (2003)²

Unpaid carers and voluntary organisations make a contribution to the health service that is valued in excess of £57.4 billion.

Carers provide the vast majority of health and community care in Britain. A 2002 study carried out by Carers UK estimated that carers were then saving the economy £57.4³ billion per year, an average of £10,000 per carer. They further estimate that two million people become carers each year.

The diagram below, provided by Baj Mathur, Chair of Hillingdon Carers, offers more up-to-date figures, based on information provided by Carers UK. Here, patients are shown at the heart of the NHS. Occupying the top two corners are Primary Care and Acute Trusts (and other associated services) costing in the region of £69 billion. Carers are at the bottom of the triangle – unheard, invisible and yet invaluable – saving the nation some £67 billion⁴.



² Source: PRTC (2003) Primary Carers www.carers.org/data/files/gpguidefinalartwork-5.pdf

³ Source: *Without Us...? Calculating the value of carers' support*. Copyright Carers UK 2002 www.carersonline.org.uk and Carers UK 'Ten Facts about Caring' <http://www.carersuk.org/Aboutus/CarersLives/Tenfactsaboutcaring>

⁴ Various sources, including 'Unpaid care worth same as £76 billion NHS' In news. Telegraph, 13 December 2005 www.telegraph.co.uk/news/main.jhtml?xml=/news/2005/12/13/ncarer13.xml&sSheet=/news/2005/12/13/ixhome.html.

The main carer's benefit is £45 per week, for a minimum of 35 hours, equivalent to £1.26 per hour.

There are currently around six million adult carers across the UK, of whom 1.25 million are looking after somebody for more than 50 hours each week⁵. There are also estimated to be 50,000 young carers in the UK - young people under the age of 18 who might be helping to look after a parent with physical disabilities or mental health problems, or who may be caring for a brother or sister with learning disabilities. More than three million people juggle care with work. Every day, another six thousand people take on a caring responsibility. Not surprisingly, people providing high levels of care are twice as likely to be permanently sick or disabled.⁶

'Carers have many more health issues than other people but they're ignored because they feel guilty if they look after themselves. Or they worry that if they are ill, people might think they can't cope and they don't want to think about that, or that someone from SS will swoop in and put their cared-for person into a home. It's an admission of failure.'

'And yet, if you don't look after the carers, they will be the patients of tomorrow.'

The Carers' Resource, Harrogate

Carers want to be recognised for the contribution they make.

Without these carers, many more people would need the support of the statutory services, and might even need residential or nursing home care or to go into hospital. Not only would this be expensive but, according to a BMA report, people's quality of life might suffer⁷. Carers report that they would like to be acknowledged for the contribution they make. Identification of their caring role by a GP is only the first step.

'There is plenty of evidence to show that carers are much more likely than the general population to suffer from injury and poor health, particularly depression, Primary care is still poor at recognising caring and the impact it has.'

Carers UK

'Value the skills of carers – carers have low social value yet £67 billion is the amount of money saved each year for unpaid work carried out by carers.'

'Focus on Carers' Conference

'GPs get paid to identify and refer to Social Services for assessment. That's very different from providing support. Lots of people don't want SS assessment, because it's so intrusive. However, if people are referred to us, we have the opportunity to gain their trust and then maybe six months down the line we can

⁵ Source: Carers UK Carers UK 'Ten Facts about Caring', www.carersuk.org/Aboutus/Tenfactsaboutcaring

⁶ Source: Carers UK Carers UK 'Ten Facts about Caring', www.carersuk.org/Aboutus/Tenfactsaboutcaring

⁷ BMA (2003) Working with carers: guidelines for good practice. www.bma.org.uk/ap.nsf/Content/carers

persuade people to have an assessment. We would like GPs to refer for support, not just for assessment.'

The Carers' Resource, Harrogate

Although there is some official recognition (in policy documents such as the *National Strategy for Carers*)⁸, recognition of their role and contribution has been sporadic and patchy across the country, with pockets of good practice.

'There have been slow, tiny improvements but these tend to be fragmented and sporadic across the country, usually dependent on individuals championing the cause. Lots of rhetoric but patchy implementation. Some good examples of joint working PCTs and Local Authority.'

Princess Royal Trust for Carers

'We have received some positive feedback from our local branches who have worked with progressive PCTs, who understand the role of carers and support them appropriately. The introduction of clinical governance must have had a positive impact on this. I suspect it meant that many local campaigners found themselves pushing on an open door.'

Carers UK

'Nationally the work of the Modernisation Agency has been important and has engaged carers effectively. The problem is enabling this to happen at regional and local levels.'

Princess Royal Trust for Carers

'At the end of the day the only way the NHS will take carers' issues seriously is if there's a target to make them do it.'

The Carers Resource, Harrogate

Despite carrying out the majority of the care needed by their 'cared-for person', many carers feel excluded from the clinician-patient relationship.

'The GP told me I was not the patient; therefore he could not deal with me! Yet my husband is not able to talk for himself. Is this a lack of care? Most patients visit their GPs for medication for their complaint. I think the GPs should be responsible for handing them a short booklet of information on what CARE is available and who provides it. Most patients and carers do not know where to go for help and advice.'

Focus on Carers' Conference

'They don't really want complaints, they just have to show that they've asked you.'

Alzheimers Society

'When the elderly lady I care for had to go into hospital, she asked them to keep me, as her carer, informed about her treatments and progress. I visited her every

⁸ Source: *Caring about Carers, the National Strategy for Carers* www.carers.gov.uk/

day. One day I asked how she was and the nurse more or less told me it was none of my business and refused to speak to me. Even when I pointed out that I was the carer, she was adamant.'

Carer, Thetford Leg Club

Simple tasks of caring for patients in hospital or the ongoing needs of chronic patients are fulfilled on a voluntary basis by carers who feel mis-used or at least unappreciated.

'Carers need to spend time in the hospital – certainly at mealtimes - people don't get fed if they are hungry because they don't know how to press the button or how to feed themselves. The auxiliaries don't consider it their job to feed people, just to put down the plates and then collect them up again.'

Alzheimers Society

'We shouldn't have to go into hospital to feed dementia patients. There is a real problem with acute hospitals.'

Alzheimers Society

Despite their detailed knowledge of their patients and the conditions that affect them, many carers are excluded from decision-making and not acknowledged as the main care provider. One woman carer, after injecting her haemophiliac husband in hospital, as she had done for 20 years, overheard two nurses complaining that she was 'interfering with *their* care of *their* patient.'⁹ Carers perceive this to be a common attitude among clinicians and NHS staff.

However, the very first step towards ensuring that carers receive the support and care they need and deserve, they need to be recognised and identified as carers. This is most likely to be done by the GP.

'GPs are absolutely vital to us. Carers are most likely to share with the GP problems caused by the caring situation. They come much more willingly when referred by GPs; we can then encourage them to look after themselves and the person they care for...'

The Carers' Resource, Harrogate

Voluntary patient and carer organisations are filling a gap.

Members of all the organisations we interviewed said that their organisation was well-placed to provide information, education and research for the NHS, and that the NHS was not performing this role.

'We have approached PCTs from time to time to address a particular problem, but to my knowledge, a PCT has never approached us or our client group.'

Cystic Fibrosis Trust

'We provide an advocacy service that lots of parents access – not tea and sympathy, which we can't afford to provide. On the whole, we are driven by the

⁹ Source: Alison Ryan's story 'Who Cares?' Patient Voices Programme. www.patientvoices.org.uk

fact that we are picking up the pieces of the NHS - and social services and educationWhere will the children with long-term disorders, mental health problems, behavioural difficulties, those in nappies, etc go? They are having to travel much longer distance to access a special school – the sickest people in the land are having to do the most in order to access healthcare and education.'

MPS Society

'It would be hard to find any clinical governance activity (outside specialist mental health services) relating to this significant need [mental health]. The professionals who see these patients do not regard themselves as responsible for meeting the need, probably because their core training has not adequately prepared them for this – it is someone else's problem. The consequence is that that need goes either unnoticed or unmet – or both.'

Age Concern

'The needs of carers are different from those of patients. Ours is the only sector that focuses on the needs of carers. The specialism of carers' centres needs to be acknowledged and carers' centres need help to survive.'

The Carers Resource, Harrogate

Patient/carer organisations consider their role to be crucial in informing their members, the patients and carers, of best practice, and of ways in which earlier diagnosis can be established. This is seen as a financial issue as much as an educational one:

'More and clearer information to patients. Best practice should be shared. Involvement of specialist organisations in planning stages of projects. Acknowledge (financially) that investment in early diagnosis will lead to improved healthcare and reduced cost in the long term.'

Diabetes UK, London

'Ring-fence budgets for specific areas of development. Share good practice/initiatives – why are all PCTs trying to re-invent the wheel for every NSF objective?'

Diabetes UK

'It seems that each PCT produces its own information when perhaps it would be much more cost effective to contact national charities such as ours who have materials written by medical experts and buy these leaflets to display locally.'

National Endometriosis Society

In some cases, voluntary organisations are demonstrating good practice, particularly in respect of working in partnership with patients and monitoring progress.

'We do an audit every month, so we have statistics and we know exactly who is getting better. We tell people what we're doing, what kind of bandage [we use] and try to educate them as much as possible so they're not just being done to... they are part of the healing process, because they have to look after themselves during the week and take some responsibility.'

There are always three of us working together, so we can observe best practice. It can feel quite threatening, because most district nurses work on their own and nobody sees their practice. But this way we can observe each other in a friendly atmosphere.'

Combs Ford Leg Club

Here's a centre that's doing it well and successfully. Why not follow our lead, despite difficulties with funding? We should be monitored, and monitored tightly. We produce good data.

Case notes are made up within 24 hours of talking to the carer. A standard form enables consistency, and qualitative data can be turned into quantitative data. Types of support are categorised against the nature of the problem, with a note of the response. Data is translated into charts of top ten needs for support. Listening and emotional support are consistently the top need.

There is a testable model of how much it would cost to provide ten hours of carer support for a general practice – and how much it would save the health service.

Carers Resource, Harrogate

'[Leg Clubs] operate as a partnership between District Nurses, GP practices, the local community, and the patients themselves. Leg Clubs provide research-based holistic leg ulcer management by addressing both the psycho-social and medical aspects of patient need. Care is delivered collectively in a social non-medical environment that facilitates socialisation and peer support and empowers patients to participate in, and take ownership of, their treatment.'

Lindsay Leg Club Foundation www.legclub.org

2 Voluntary organisations can complement NHS services by providing patients, carers and clinicians with expertise, information and support.

'Approaching a PCT would be an unknown and intimidating quantity for lots of people. Voluntary organisations can engage more directly with users and entice users to engage with CG issues.'

'Voluntary organisations could also be tasked with finding out views of service users, collecting and feeding back these views to CG.'

Age Concern

Voluntary organisations do work with PCTs to ensure that clinicians have appropriate information about specific conditions, but examples are not widespread.

Members of all the organisations we interviewed said that their organisation should provide information, education and research for the NHS, because they are not doing enough of it themselves.

'Patients can help with education. Age Concern can help to encourage people to talk about their experiences, their lives, their expectations, and portray their experiences in a rather different way from that which may be expected of older people. So Age Concern is not just a service provider, but can also be the voice of older people, communicating the views of older people.'

Age Concern

'PCTs could ensure that, wherever there are local support groups, patients should be made aware of them. We can work alongside of each other, but PCTs seem to feel threatened.'

National Endometriosis Society, Dorchester Branch

'The way forward is training, education, awareness – for doctors and carers and clinicians – and funding for it.'

Alzheimers Society

'GPs need to be educated. It's such a complicated disease.'

National Endometriosis Society, Cambridge

'There needs to more education of GPs so they are more aware of the condition. Every GP can diagnose appendicitis, but they should know enough about endometriosis to at least suspect it. They should know the right questions to ask. There could also be seminars (organised by PCT) with attendance from at least one GP from each practice. Then they could go back and pass on information to others in the practice, so they could realise that they aren't asking the right questions, or missing symptoms.'

National Endometriosis Society, Dorchester

'The support group should empower patients to learn how to get the best from the system, from the doctors.'

National Endometriosis Society, Cambridge

'A doctor asked me if people with dementia got depressed – I said "Well wouldn't you?!" So you're up against ignorance – he was supposed to be a trained physician.'

Alzheimers Society

'Eventually I found BPA on the web, because I desperately needed some support, some information, but I didn't know it existed. Nobody told me.'

Blood Pressure Association

Where PCTs are able to work with voluntary organisations to share and disseminate information, this can work well.

*'There is ***-all information available to patients from GPs. The BPA has GP packs to send to doctors. There is a poster that should be in all GP surgeries from BPA.'*

Blood Pressure Association

'The NOS is able to act as a resource. Best practice examples are available to those who ask, protocols and guidelines can be shared, cutting down on workload for PCTs interested in implementing service improvements in Osteoporosis, diagnosis, treatment and care.'

National Osteoporosis Society

'It would be quite nice if they could give you some info, and tell you about support that's available. A simple leaflet [like ours] could tide you over until your follow-up appointment.'

National Endometriosis Society, Dorchester Branch

Patient and carer groups have an appetite to work more closely with PCT working groups but, as yet, few PCTs engage in a consistent and co-ordinated way.

We asked patient and carer groups about the degree to which PCTs involve them in their processes. It is clear from the patient groups we consulted that there is a willingness for much greater partnership. 12 of the 14 groups surveyed responded that PCTs could engage more effectively with them. 11 groups consider that they could work with PCTs more effectively to meet the needs of patients and carers, and 9 feel they could do so to better improve access and reduce health inequalities.

'Some PCTs are very good and others see voluntary orgs as a threat or as non-professional and interfering.'

Diabetes UK Yorkshire

'To be involved routinely in planning meetings as an equal part of the team.'

Diabetes UK, Yorkshire

'All PCTs in our area geographically include us in their committees in our area of concern – invite us to participate in relevant events they plan.'

Diabetes UK, London

'We would like to relate to far fewer organisations – say 8 to 12 rather than over 300. We would like to relate to organisations that take an interest in and understand the importance of appropriate treatment for CF. We would like to deal with an organisation that is interested in the quality of the service offered and not just costs.'

Cystic Fibrosis Trust

'My efforts to communicate to PCTs an initiative that addresses core elements of Clinical Governance have met with minimal response. Although the Leg Club model has been widely published in the professional journals, offers to attend and present to PCT managements have received no interest and often no acknowledgement or reply.'

The Lindsay Leg Club Foundation

'We have approached PCTs from time to time to address a particular problem, but to my knowledge, a PCT has never approached us or our client group.'

Cystic Fibrosis Trust

At best, support groups consider that they can complement NHS services and help to improve them by providing patients, carers and clinicians with expertise and information services. It is their view that consultants and GPs within PCTs can really benefit from greater involvement with these groups, both educationally and in terms of a cost-saving to the NHS from earlier diagnosis and less sick leave among chronic patients who are treated inappropriately.

'The consultant's view is that there is a real role for support groups like this to work in partnership with the NHS, to make it possible for patients to learn and come in contact with consultants outside the consulting room.'

National Endometriosis Society, Cambridge Branch

'How can we educate GPs, medical students? In New Zealand, an endometriosis rep goes to colleges and schools and talks to young girls to educate them – there are plans to talk to medical students as well. Susan Evan (from Adelaide) has written a book about endometriosis.'

National Endometriosis Society, Dorchester Branch

'If there isn't time for the GP to talk to you, they should send you to the BPA, or relevant organisations. So the GP ought to know where to find the information.'

Blood Pressure Association

'[We need more] self-management programmes – like the Expert Patient Programme – women need to be empowered to take control. After a six week course women have less pain, need fewer appointments, and are generally much better. We ran courses here, but couldn't get enough women to sign up –

presumably because GPs and consultants weren't passing on the information! So people don't know about it.'

National Endometriosis Society, Dorchester

'I think the way forward is not just educating health professionals, but also educating patients, which is part of the role of the support group. Patients need to understand that actually health professionals have not got all the answers, and for something like endometriosis, where there is no cure, they are there to help us manage our symptoms as best we can.'

National Endometriosis Society, Cambridge

'After ten years of providing specialist carers' support and monitoring many aspects of it, there is no doubt that GPs provide the most vital link with carers. If GPs will encourage carers to seek and accept our help as a specialist carers centre, then we can signpost the carer and the cared- for person to a range of services that will help them to care better and longer , more happily...'

The Carers' Resource, Harrogate

Voluntary organisations say that they could work with PCTs to meet shortfalls in some service provision which, although it might require some funding, could result in a more efficient service. For example, through care and education programmes, sharing initiatives between PCTs and better liaison between primary and secondary care organisations.

'The NHS could help with funding, as the financial side is a bit difficult. We just cover the cost of the hall. I bring in cakes and sandwiches each week and have done right from the start.'

Combs Ford Leg Club

'I don't think it's sensible or reasonable to ask each PCT to determine appropriate levels of care for the sprinkling of CF patients who live in their area. That having been said, they could fund this care properly. As it is, patients attending the same specialist centre are sometimes receiving different levels of care because of what their PCT will or will not pay for.'

Cystic Fibrosis Trust

'At PCT level by involving carers and carers' representatives as partners in planning of local services and in training staff. At GP level by proactively identifying carers and plugging them in to appropriate services.'

Princess Royal Trust for Carers

'Dr Fosters' survey highlighted a number of shortfalls in service provision. As a result we have questioned the PCTs and hopefully progress will be made. We also encourage our membership to press for an adequate number of user representatives on the appropriate committees.'

Diabetes UK

'Where adjacent PCTs are struggling to provide a particular service, they should consider joint management that should be both more efficient and a cost saving

to both. Secondly, best practice in some PCTs should be shared with struggling PCTs – they should work together and not compete.’

Diabetes UK London

‘More funding. Better liaison between primary care organisations and secondary care. More proactive in bringing down barriers between these organisations.’

Diabetes UK

‘We need to be recognised as a professional service. Funding from the PCT would help. The PCT needs to recognise how much we are part of these teams. We get referrals from clinics we don’t even go to.’

The Carers’ Resource, Harrogate

Mutual engagement between PCTs and patient/carer support groups elicits mutual benefits

In terms of the improvements which voluntary patient and carer organisations would like to see made by PCTs to engender greater involvement, their key message is: better communication, through proactive contact and through a more cohesive and centralised approach to communication.

‘We get referrals from a variety of HCPs, including cancer specialists, Macmillan nurses, community nurses, stroke clinics, community rehab team, child development – so we must be doing something right.’

‘We’re very important to a few people who have grasped just how important carers are.’

The Carers’ Resource, Harrogate

‘In general, the communications are one way! However, once a relationship has been established, some PCTs are open and welcoming.’

Diabetes London

‘We can help raise awareness among people with asthma and health professionals but for better access to happen asthma needs to be given a higher priority in the majority of PCTs, not just an enthusiastic minority.’

Asthma UK

‘Improvements vary from PCT to PCT with respect to user involvement and structured education. Improvements include: invitations to strategy days, protected learning events and working with us to set up groups’.

Diabetes UK North West Region

‘There could be far greater engagement at all levels: national, regional and local. Frequently it is a matter of building in areas of best practice that could be transposed across the country.’

Princess Royal Trust for Carers

‘PCTs could ensure that, wherever there are local support groups, patients should be made aware of them. We can work alongside of each other, but PCTs seem to feel threatened.’

National Endometriosis Society, Dorchester

'Information shouldn't be drip fed, eg. If you become a carer suddenly, you may not discover for two years that it's possible to have a paid worker to bathe and dress the patient. '

Quality dashboard participant

'There is some engagement with voluntary organisations (such as Age Concern) when there is a key policy issue or some large-scale activity, for example, in developing the NSF for Older People. Most local Age Concerns have been involved in consulting, developing, implementing and now delivering the NSF.'

Age Concern England

'Some PCTs around the UK have supported our regional specialist clinics for MPS diseases, enabling MPS experts to work alongside local paediatricians and adult physicians. This has resulted in patients and their families having more local access to expert medical help.'

MPS Society

Nevertheless, improvements are asked for in terms of the level of involvement and commitment to communication and consultation:

'Involve us more and have confidence in our expertise.'

Diabetes UK London

'Improve communications with what they are planning to do and what they have achieved with service users. Respect and pro-actively seek service users views over a greater area, and use data (BMT Communities/parents of children/rural communities/GP practices locally). Ask more often.'

Diabetes UK East Midlands

Communication is not only seen as a one-directional process, but as a consultative one:

'They could develop a better engagement with our organisation and the public by having PCT-wide consultation meetings. This would enable PCTs to have a better idea of what care is being delivered.'

Diabetes UK

From our survey of voluntary organisations, there were some examples of improvements in the quality of healthcare provided by PCTs through making use of patient/carer organisations.

'Where user reps have attended our training, they are more able to contribute effectively.'

Using our literature to give to patients.

Completing Dr Foster survey and acting on findings.'

Diabetes UK, Northern and Yorkshire

Only four of the organisations surveyed had been involved in clinical audit. While some changes are considered to have been made as a result of clinical audit or other elements of Clinical Governance, not many examples were given in the research:

'Structured education programmes available, services moved to primary care, retinal screening programmes in place.'

Diabetes UK, Yorkshire

'NSF has enabled PCTs to focus on specific areas. Best target retinopathy – much effort made to reach required targets, however still many local PCTs struggling to reach the requirement – especially poor service throughout [the county].'

Diabetes UK, East Midlands

Patients, carers and voluntary organisations want PCTs to be involved in support groups

The quality of care on this level is not just seen by patients and patient groups as an individual clinician's responsibility. It is at PCT level that change can happen. PCTs are engaging more with the voluntary organisations as a result of Clinical Governance, but twelve of the fourteen organisations consider that PCTs could engage more effectively.

'Since the introduction of regional management 18 months ago, PCTs are more aware of organisation and support is available, although it is limited. Make more use of website and careline for information and organisational policy/position on services. More requests to help initiate/support events to engage service users – overwhelming requests for public meetings/consultations/group support/user reps/education events for people with diabetes.'

Diabetes UK, East Midlands

'The PCT's could all identify a carer's lead. That person could become a member of Carers UK and keep up to date with policy changes and best practice from around the UK.'

Carers UK

'Those that haven't responded should do so. If they are planning an event/training in our field of interest, the very least they could do is inform us better to include us in the planning.'

Cystic Fibrosis Trust

'PCTs have sometimes denied treatment options including expensive drugs, home care support for patients on intravenous antibiotics and the choice of a particular specialist CF centre to CF patients who live in their catchment area. By engaging with us they would learn that this results in sub-optimal care.'

Cystic Fibrosis Trust

'PCTs could gain more understanding of what care is being delivered by organising joint public involvement events on an annual basis for all communities.'

Diabetes UK

3 Patient and carer organisations display some awareness of the principles of clinical governance but individual patients and carers have little or no understanding of clinical governance and, on balance, report unsatisfactory experiences of care.

'I was also asked whether "clinical governance" was really the ideal phrase for what we are trying to achieve; doesn't it imply that it's a concern only for those who work as clinicians? Well, maybe in some way it's not the ideal term, but it has become an established part of our vocabulary. Increasingly, I define clinical governance for people as "assuring the sacred duty of trust for patients", and it's a duty incumbent on everyone who works for the NHS, in whatever capacity. If you think about it like that, you see clinical governance as a concern for everyone.'

Aidan Halligan

www.cgsupport.nhs.uk/diary/1@Bolton_25th_Feb_2005.asp

Patient and carer groups generally understand the meaning of Clinical Governance in terms of the PCT development path (twelve of the fourteen responding organisations surveyed felt that the term resonates with them), although it is not considered a 'comfortable' term and, even at organisational level, there is uncertainty. One CEO of a voluntary organisation delayed completing the questionnaire and eventually phoned to say:

'Clinical governance in primary care – I don't really understand what that means.'

While individual patients and carers understand the *concept* of clinical governance as it pertains to them in terms of the quality of care they receive, they do not necessarily consider that they experience high quality care from the health service.

'Quality in healthcare means that you should be seen by the right person, at the right time (on time), be fully informed as to your health situation and all the available options of treatment, be treated with sensitivity and respect and to be looked on as a human being not "an interesting case". Basics like being seen in a clean, unthreatening environment are a given.'

Patient with kidney disease and chronic fatigue syndrome

Clinical governance makes little difference to the quality of care in practice

Regardless of the level of understanding, in many cases, organisations do not consider that clinical governance is a path being followed by PCT Boards in practice. The following comments are typical.

'It is not really possible to attribute any improvements to clinical governance. There have been gains and losses in patient engagement over the recent years. It is not clear that there has been a net gain in this respect nor is it possible for us to attribute any improvement to clinical governance.'

Asthma UK

'There's been no improvement, no feel-good factor for patients, nothing has really changed since advent of clinical governance.'

MPS Society

'Clinical Governance engagement is pretty limited and is more likely to be viewed as an internal issue between people of the same profession, where meetings are held behind closed doors.'

Age Concern England

'Few carers understand the term (Clinical Governance) and it has quite a medical connotation. It is not user- or carer-friendly.'

Princess Royal Trust for Carers

'At a PCT level our members have seen little or no improvement in Clinical Governance in patient/carer care. We are still seeing young adults with complex needs put on geriatric wards in general hospitals...'

MPS Society

'The PCT isn't really interested, apart from an initial bit of funding. I attended a special meeting and bid for some monies available for innovative community based groups. The PCT did donate half the cost for a new Doppler ultrasound machine. We've never been audited and they haven't put in any more money, although the ulcers are definitely improving.'

Combs Ford Leg Club

'It has to be welcomed, but it has its limitations. I do not believe it is promoting excellence, but mediocrity in many instances.'

Cystic Fibrosis Trust

Five of the patient/carer groups rate the extent of improvements in patient care they have seen as a result of Clinical Governance at 3 out of 5 (where 5 = considerable and 0 = none at all). Five give this question a lower rating and only two give it a rating of greater than 3.

Patient and carer organisations report examples of improvements in respect of:

- education and training

- systematic services
- better consultation with patient groups

as illustrated by the following comments:

'The move of majority care into primary care from secondary/hospital based services and the education and training for primary care staff.'

Diabetes UK Yorkshire

'Nationally the work of the Modernisation Agency has been important and has engaged carers effectively. The problem is enabling this to happen at regional and local levels.'

Princess Royal Trust for Carers

'Mailing patients informing them of public consultation meetings through registers. Presentations pre-event by CEOs of PCTs and structured education surveys.'

Diabetes UK

'Engaging with clients may help PCTs to understand that many patients are presenting with challenging medical and care needs.'

MPS Society

'Some PCTs have undertaken questionnaires at secondary and primary care levels looking for feedback.'

Cystic Fibrosis Trust

'Implemented methods of identifying and referring carers so that carers can have access to services, be identified and referred for support;

Introduced carer-friendly policies.

Devised a strategy for joint working.'

Princess Royal Trust for Carers

Clinical governance is often regarded as a stick to beat PCTs with

It isn't clear from these patient groups whether they consider that PCTs do have an ongoing Clinical Governance dialogue with healthcare and social care providers. Seven of the fourteen respondents report having seen some changes in their organisation's relationship with PCTs since the introduction of Clinical Governance. There is a view that Clinical Governance is a directive or tool that both patients/carers and the Department of Health can use to beat PCTs over the head in an attempt to enforce change in the services they receive.

'The term implies a directive and motion from the DH to improve standards of care. The term is often quoted by clinical leads as a benchmark in achieving quality service delivery.'

Diabetes UK

'Clinical Governance can be used as a negotiating tool to ensure appropriate and safe care although this is rarely invoked in practice and when it is, it may be ignored.'

Cystic Fibrosis Trust

'PCTs appear to be more concerned that they comply with clinical governance policy or targets. Discussions regarding service improvements / failures, when considered under clinical governance, appear to be taken more seriously.'

National Osteoporosis Society

Improvements are 'patchy'

Some improvement in PCT performance is noted by patient and carer voluntary organisations, but this is considered 'patchy' at best. Most improvement is seen in the areas of PCT staff training and PCT commitment to interaction with voluntary groups.

'We have received some positive feedback from our local branches who have worked with progressive PCTs, who understand the role of carers and support them appropriately. The introduction of clinical governance must have had a positive impact on this. I suspect it meant that many local campaigners found themselves pushing on an open door.'

Carers UK

Seven of the fourteen patient/carers groups consider that PCTs are encouraging providers to work towards NHS Improvement Plan targets, though again, there is no consistency in responses – some are concerned about the patchiness of PCT performance.

'There have been slow, tiny improvements but these tend to be fragmented and sporadic across the country, usually dependent on individuals championing the cause. Lots of rhetoric but patchy implementation. Some good examples of joint working PCTs and Local Authority.'

Princess Royal Trust for Carers

'PCTs have not set such targets. Some working parties or strategic health authority groups or specialised regional commissioners, sometimes involving PCTs have set targets'

Cystic Fibrosis Trust

'Because of the need to meet targets, you have to phone on the day and can't see your own GP. In many cases this is ok, but families with MPS can't plan a scheduled appt five or six days in advance. As a result, most parents bypass primary care and manage it through tertiary centre and phone calls at home.'

MPS Society

'Members of the public are so aware of targets in hospital. There's a concern that you will be 'ticked off' without necessarily having the best treatment. If you don't count towards their targets, then you may not get the help you need.'

National Endometriosis Society, Dorchester

Patient groups have limited experience of clinical audit and clinical risk assessment

Only four out of fourteen organisations studied claimed to have been involved in a clinical audit, one of which was internally initiated, and not conducted through a PCT.

'We have conducted our own clinical audit and also fund a clinical database. Cystic Fibrosis has improved in some areas as a result. Some patients including the 5 expert Patient Advisers employed by the CFT have been involved in scoping exercises and service reviews.'

Cystic Fibrosis Trust

'Diabetes UK Central Office was involved, and we were involved in the past with CHCD on Diabetes Appraisal in the North West.'

Diabetes UK North West Region

Only three out of fourteen organisations claim to have been involved in clinical risk assessment:

'We develop Standards of Care documents which have been used to improve patient safety and to minimise risk.'

Cystic Fibrosis Trust

'Risk assessment is a case in point. Whose risk is being assessed and managed? Supporting people to take medication at home is a particular problem (i.e. when they can't physically access or administer the medicine). Social care staff don't do it because they say they are not trained. District nurses don't do it because they say it's not their job. Most medication support is, of course, done by family and friends with no formal training – so who is at risk?!'

Age Concern

'When I asked why he couldn't just set my wrist, the A&E consultant said "The reason I'm taking the precaution of doing follow-up scans and x-rays and not just setting your wrist in plaster is, to be honest, so you won't sue us for negligence."'

Patient¹⁰

¹⁰ Source: *Clinical Governance Matters* written by Pip Hardy and Ross Scrivener and published by the UK Health Education Partnership in 2004. www.ukhep.co.uk

Public consultation should result in improved care

There is a mixed level of support for the improvements in the way PCTs engage with client groups. Only one in fourteen respondents considered the improvements to have been considerable, while five rate the improvements at 3 out of 5 and six give them lower scores (three claim there have been no improvements at all). Twelve of the fourteen respondents consider that PCTs could engage more effectively with their groups.

Among examples of improvements which have been experienced by the patient organisations are:

'Mailing patients informing them of public consultation meetings through registers. Presentations pre-event by CEOs of PCTs and structured education surveys.'

Diabetes UK

'Engaging with clients may help PCTs to understand that many patients are presenting with challenging medical and care needs.'

MPS Society

'Some PCTs have undertaken questionnaires at secondary and primary care levels looking for feedback.'

Cystic Fibrosis Trust

'Implemented methods of identifying and referring carers so that carers can have access to services, be identified and referred for support; Introduced carer-friendly policies. Devised a strategy for joint working.'

Princess Royal Trust for Carers

'Some commissioners have "listened" to the arguments put forward about why PCTs should begin to implement Integrated Falls and Osteoporosis services, however, little of this discussion appears to have resulted in service development being implemented.'

National Osteoporosis Society

While six of the fourteen patient groups responding to this research have been involved in public consultation, only two of these feel that patient care has improved uniformly as a result.

'We've held 30 public consultation meetings over the last 3 years with PCTs (17 planned for next year). Between 150-400 people with diabetes, carers and families attending. Care has improved in some areas with additional HCP resources.'

Diabetes UK

'We wrote to PCTs providing information and yet when applications for funding were made to the same PCTs they said they were uninformed. I guess our letter and information went in the bin.'

MPS Society

'Volunteers and user reps have been included in this process within a few PCTs, but it is not common practice.'

Diabetes UK, East Midlands

'There could be more effective engagement at national, regional levels with the Primary Carer Development Team and local engagement with PCTs. Carer protocols and plans could be made at all levels.'

Princess Royal Trust for Carers

'Some user reps involved across the region in various PCTs. When involved, feedback suggests healthcare professionals find their input very rewarding/enlightening.'

Diabetes UK, East Midlands

'CG should have some sort of lay and user leadership, which would present a powerful message about the purpose of CG. CG committees could be chaired by a lay person or service user. For example, a local Diabetes UK person could chair a group, to provide appropriate focus, rather than CG just benefiting clinicians. This could help to ensure consistency of standards of service delivery.'

Age Concern

These are the right areas for change, but patient and carer groups are looking for greater involvement and communication with PCT staff through more cohesive and centralised approaches to communication. This is particularly true for people who may need additional communication support.

'They keep advertising meetings and asking us to go along, but they never say there's going to be an interpreter there. They just wait until we ask for one.'

Cintra

'They haven't invited us. What's the point of going to a meeting if you can't understand what's going on?'

Cintra

Support groups consider that they can complement the health services in the education of patients and carers, and that clinicians can benefit from participation in this process, helping early diagnosis and saving money. Most organisations have offered suggestions as to how this might be done, such as the following:

'[PCTs could] understand that spending £1.7 billion per annum on treating unnecessary fractures, should be spent instead on identification of osteoporosis and treatment to limit fractures.'

'Once understood, put energy into implementing relevant services to deliver.'

National Osteoporosis Society

'A lot of consultants will give you a diagnosis, but then it's up to the patient to find out more about it. The only leaflets around even now are the ones we've left around. It would be quite nice if they could give you some info,

and tell you about support that's available. A simple leaflet could tide you over until your follow-up appointment.'

National Endometriosis Society

Patients believe that targets and financial constraints are more important to the NHS than the quality of care

'Is £2.50 per day too much to spend on an old person?'

Alzheimers Society

Although individual patients do not feel directly involved with the financial state of the health service, and individual patients' experience of the internal workings of PCTs is very limited, there is a clear understanding that financial constraints on PCTs affect both the level of service and the freedom of consultants to perform expensive procedures, or conduct research. For example, particular concern is expressed over the NICE decision that Aricept, at £2.50 per day, is too expensive to prescribe for people with dementia, despite its proven efficacy in many cases.

'In the rare disease arena, there is a sense of euthanasia by the NHS if the disease is too expensive to manage/treat. Loving carers go to prison for helping patients to die but it is permissible in the NHS.'

MPS Society

'Financial constraints, real or imagined, have an effect on service provision.'

Diabetes UK, London

'In 1995 it took an average of seven years to get a diagnosis. Now it takes an average of nine years. There are too many diagnoses of IBS. If you go privately, you can ask for a second opinion, but you shouldn't have to pay to have this choice.'

National Endometriosis Society, Stockport

'Lots of people have had problems with GPs getting the attention that's needed. If the PCT can't pay for another hospital, then you have to stay where you are. So much for choice!'

Alzheimers Society

'If I had the money I would go privately, instead of which, I feel like a guinea pig.'

National Endometriosis Society, Cambridge

'You don't really get care, you get apologies or puzzled faces. One hospital doctor has made a big effort on that front but he is getting more from me, from a research point of view, than I am from him and he can't get a grant to do more research into CFS at the moment anyway.'

Patient with kidney disease and Chronic Fatigue Syndrome

'We were on our way to the European Court of Human Rights when the Health Ombudsman intervened and we went to mediation and won the case, for an appropriate supply of nappies and disposable gloves. This family was dealing with two Sanfilipo men of 17 and 21, both doubly incontinent, both with mental

disorders, with no support from the PCT, no incontinence sheets, only four nappies a day and no disposable gloves.'

MPS Society

'When asked about choice of consultant, the Primary Care Trust doesn't care. Women can be referred to him, but he is not allowed to do surgery. They've closed his books – now the Trust is saying they aren't cutting the service because the service was never there, but it's because they've realised how expensive it was.'

National Endometriosis Society, Stockport

'Although some research is being done at the moment, no extra money is being put in by the government (in fact the amount of money has reduced over the last few years). Although it is not life-threatening, it does result in a lot of time off work and people can be extremely ill.'

National Endometriosis Society, Cambridge

'They're really only interested in people suffering from coronary thrombosis. When I asked if they did anything for heart failure, they said "No, I don't think so." Nobody is concerned with how to help these old people with heart failure to live rather better lives.'

David Clarke 'Don't you do anything for heart failure?'¹¹

¹¹ Source: Patient Voices www.patientvoices.org.uk

4 Respect, listening and communication from clinicians are essential to improving the patient experience.

The values that inform and permeate clinical governance policies and implementation guidance are:

- *humanity*
- *equity*
- *justice*
- *respect.*

These principles should characterise the way a PCT responds to its patients, its communities and its own staff groups and to partner organisations. Like the process of caring itself, clinical governance needs to engage the emotions of all staff and harness their energies in the pursuit of excellence.¹²

The Strategic Leadership of Clinical Governance in PCTs

Insensitivity and ignorance among clinicians are common complaints

It is insensitivity and ignorance among clinicians which is the greatest complaint throughout this study.

'A lot of consultants/doctors who deal with women's problems are male. How can they be in that profession when they don't even have a monthly cycle? How can you possibly understand if you don't have any experience?'

National Endometriosis Society, Cambridge branch

'Last time I went to my doctor, he said "Don't waste my time." Somebody goes with me, and I don't do much talking. If I say 'I don't want to see that doctor' they don't pay any attention. He ignores you and doesn't talk with you. He acts irritated.' He's a bully.'

African Caribbean Elders Group

'Around a half of sufferers feel their doctor does not take the pain seriously – especially those with a longer diagnosis delay and where the GP doesn't listen.'

National Endometriosis Society

Within the various voluntary patient groups involved in this research, there is mixed support for PCTs' work. Those in the Diabetes UK organisation have generally more positive views than those in the Endometriosis Society, Alzheimers Society, Age Concern or Cystic Fibrosis Trust. Of these, only Diabetes is a national target.

These organisations represent people who, all too often, experience:

¹² Source: Stanton, P. (2004) *The Strategic Leadership of Clinical Governance in PCTs*. National Clinical Governance Support Team.

- frustration caused by ignorance among clinicians and carers
- marginalisation by a system unable to cope with specialist needs groups and smaller organisations
- at worst, callous treatment by consultants and others who can be chauvinistic and arrogant.

'I've been managing my asthma for 30 years and I carry an inhaler in my pocket all the time. I also like to keep one in the car and one as a spare – that seems only sensible. So why can't they trust me when I tell them I need another prescription instead of making me feel like a criminal drug abuser?'

Asthma patient

Fundamental to patients' experience of care is the level of respect accorded them as individuals. Indeed, a 2004 MORI poll¹³ researching public perceptions of the NHS revealed that patients care much more about being treated with dignity and respect than they do about mortality rates, and this includes people who may need communication support.

'Why do they ask the interpreter what I want instead of asking me?'

Cintra

This isn't simply about politeness and consideration, but refers to their credibility as an honest person who isn't imagining their symptoms. There are apologists for the lack of respect experienced in the health service, those who are prepared to excuse doctors who forget what tests they've asked a patient to have or who are very late for appointments, and men who aren't able to comprehend women's experiences. But the single aspect of care about which patients feel most aggrieved is the lack of respect with which they are treated.

'They could be a bit more understanding when you go and are obviously in pain that is affecting your whole life.'

National Endometriosis Society, Cambridge

'Your confidence is so undermined by people who think they are god and behave like god, take no care, no time. I have enough pain, without emotional hassle as well.'

National Endometriosis Society, Stockport

'I went to the doctor with severe back pain and she said to me "Back pain? It's just wear and tear. At your age you've got to expect it." I was only 49 then. I later went to an osteopath who diagnosed severely pulled ligaments.'

Patient¹⁴

'My two year-old daughter was booked to have an operation to correct a severe convergent squint in her right eye. When she came round from the operation, I

¹³ Page, B. Mori Research Institute Director (2004) 'What they really want' *HSJ* 8th April 2004.

¹⁴ Source: *Clinical Governance Matters* written by Pip Hardy and Ross Scrivener, published by UK Health Education Partnership in 2004 <http://www.city.ac.uk/ukhep/>

was surprised to discover that they had operated on the left eye. When I remarked on this to the surgeon (who was not the person I had expected to perform the operation), he looked a little flustered and then told me that it didn't matter which eye you operated on – it was just like aligning the tyres on a car.'

Mother of young patient¹⁵

'There are instances where you can feel frustrated or patronised because it's so much easier for them to say 'you're depressed' than it is to take time to understand you're not depressed and you've nothing to be depressed about apart from being ill. It's hard to feel respected when you know full well you don't have a psychosomatic illness and you see people who want to label you depressed out of sheer laziness.'

Kidney disease/CFS sufferer

'He didn't even acknowledge the treatments she had had, asked why she might want to have her ovary removed from the rear wall of her abdomen! He had so little sensitivity.'

National Endometriosis Society, Stockport Branch

'In her first consultation with [consultant], he didn't even look up from his notes – after she had waited for three hours for a five minute 'chat'. So then she went privately [to see the same consultant!] and is seen on time, spoken to, respected.'

National Endometriosis Society, Dorchester Branch

Carers and patients *want* clinicians to respect them, to recognise their contribution to their own care and to show a realistic approach to dealing with patients' real, everyday issues of care, rather than eschewing the prosaic detail of a patient or carers' daily suffering for the academic and impersonal glamour of a research-centred approach.

'The individual knows their own body, they know their own tolerance of pain, their own tolerance of discomfort, they know what side effects they're prepared to put up with, what side effects they're not prepared to put up with and it's really for them, I think, to call the shots in negotiating a course of treatment.

But we as patients can't do that, unless there's a full disclosure of the information and unless we as patients are prepared to shoulder the responsibility of learning what we need to know to make the decision. But equally the clinician has to be willing to respect our expertise, which is on our own feelings.'

Ian Kramer, expert patient¹⁶

'Since I've been telling the consultant and GP what I want, things have been better.'

National Endometriosis Society, Cambridge branch

¹⁵ Source: *Clinical Governance Matters* written by Pip Hardy and Ross Scrivener, published by UK Health Education Partnership in 2004 <http://www.city.ac.uk/ukhep/>

¹⁶ Source: *Clinical Governance Matters* written by Pip Hardy and Ross Scrivener and published by the UK Health Education Partnership in 2004 <http://www.city.ac.uk/ukhep/>

'My doctor told me off for asking too many questions, and instead displayed me to a lot of other doctors and students. While I want doctors to be able to learn about my condition, because it's quite rare, I don't want to be poked and prodded unnecessarily. They asked me if I was going for the world record for the number of specialists?!

Am I a person or just an interesting case?'

Blood Pressure Association

'I've been managing my asthma for 30 years and I carry an inhaler in my pocket all the time. Why can't they trust me when I tell them I need another prescription instead of making me feel like a criminal drug abuser?'

Asthma patient

While it is GPs and specialists who come in for most frequent criticism, as the people holding the most power, nurses and auxiliary staff can be thoughtless, ill-informed and, at worst, inhumane.

'Carers who come into people's homes aren't properly trained – they don't lift or move people properly. I know they have NVQs, but they don't know what to do. There's a lack of knowledge about the specialist care of people with dementia.'

Alzheimers Society

'A good nurse is a credit to the community. They would want to meet the patient needs first and do all they can... Also communication is the key to getting things done... i.e. GP, nurse and patient. A bad nurse is a person who doesn't listen to their patients when there is a problem or in pain... Also rushing the job instead of giving patients care... Always watching the clock instead of giving quality care... Not following procedures properly can be fatal to a patients life... Also administering wrong medication due to not taking care & attention to patients care plan or patient notes...'

Focus on Carers' conference

'Raising awareness with hospital nurses – a diabetic told his story of living with diabetes and explained how disempowered he was each time he went into hospital. He immediately had his insulin taken away, and of the complications and stress this caused – because nurses knew best!'

Diabetes UK, East Midlands

'Patient empowerment is not an easy concept, and it is inevitable that some nurses and nurse managers are very uncomfortable with the notion of moving from a 'nurse dominant /patient passive' relationship to one of an equal partnership in care. Public commitment to the ideals of community involvement and patient empowerment is often not matched by support for the reality of its implementation. Integrated teams are the way forward, Therefore there should be less emphasis on protecting rigid professional roles when responding to patient and community needs. Empowerment dispels the 'nurse dominant / patient passive' relationship, thus ensuring a true partnership in care.'

The Lindsay Leg Club Foundation

'A friend of mine is blind and deaf. He went into hospital but nobody told him, when they brought his food, where his knife and fork were, or what he was eating, Same with drink – never told what anything was, or where anything was, despite staff knowing he was blind, but he was just left to grope around and he found this very stressful. He felt as though he was constantly reminded that he was someone with disabilities as though he was having his nose rubbed in it.'

Quality Dashboard participant

Consideration and respect engender confidence and positive views

'When I went to see [the doctor], it was like a breath of fresh air. He believed me. He was kind and considerate and recognised the bad things. When he didn't know the answer to a question, he said so, but offered to find out.'

National Endometriosis Society, Stockport

Clinicians' involvement generates more than an improvement in healthcare. It engenders confidence and positive thinking among patients who otherwise feel disenfranchised. The personal commitment of a medic can change a patient's life, even if they cannot cure the ailment.

'I came off the phone and felt like a weight had been lifted off my shoulders. Somebody understood. It was very comforting. This has been a better source of information than anything the NHS has given me.'

National Endometriosis Society, Stockport

'My GP is good because his mother had Alzheimers so he's interested. That's worth more than years of training. It's really a matter of having experience with dementia – if you just read about it in books, you don't understand.'

Alzheimers Society

'My husband's GP was wonderful – he was very understanding and listened to what we were saying. He said "if at any time I wanted to go and chat to him even if we can't do anything, just come and have a chat." So he was looking after the carer as well. They said to call at any time.'

Alzheimers Society

'I've rung the doctor when the carers didn't take care when putting my husband to bed, when his pyjama top was crumpled – I know it's just a small thing, but I was worried that it would be uncomfortable. The GP reassured me that perhaps it wasn't so important to my husband, but he wrote to me when my husband died and he was wonderful.'

Alzheimers Society

When patients come across respectful care, they are so grateful, they put all other experiences aside.

'He formulates a plan for your care that is planned around your lifestyle, and your needs. He offers options (guided options) and information, based on your history.'

You get listened to. Everyone else will make you feel that the disease is in your head.'

National Endometriosis Society, Stockport

'In some ways you could say I had excellent care from the NHS. The consultant said he could not help, there was no treatment for MS at the moment and sympathy was all he could offer, but he spent over an hour with myself and my wife. Giving a second opinion - the doctor said she could only give me five minutes but she gave me a list of organisations to contact and a book to take away and read. I felt respected as an adult and treated with dignity – oh the second opinion was in the states - how it should be done.'

Focus on Carer's Conference

'I've been coming here for a year. At my last clinic, I never saw the same nurse twice but here there's good co-ordination. If you see strangers, they've only got notes, but here they know who you are and they take photos as well.'

'There is excellent care at our doctors, and the nurses are wonderful. They care about you – directly you walk into the surgery, they listen to you and talk to you.'
'I give them 200 out of 100 – they are marvellous, so kind and helpful – it's like a little family gathering.'

Combs Ford Leg Club

'I had to change consultants, because he intimidated me. I was on my own and he just said, basically 'If you don't take the pills, you'll die.' But I couldn't take the pills because I was having such bad side effects. So I changed consultants, and now they are lovely and are trying very hard.'

Blood Pressure Association

5 Patients want, and expect, to experience seamless, person-centred care

'The NHS Plan sets out our ambitions to create a patient-centred NHS. Our vision is to move away from an outdated system towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement. Our goal is to move away from a paternalistic model of decision making towards a model of partnership, whereby citizens have a greater connection with their local services, and have a say in how they are designed, developed and delivered.'

DoH (2001) *Shifting the Balance of Power: Securing Delivery*

Patients have only one journey through the NHS but are conscious of a lack of joined-up thinking and working

Patients are troubled by 'gaps' and lack of joined-up thinking, although they are not particularly aware of the divisions between primary, secondary and tertiary care, except when

the gaps become obvious. Carers are, inevitably, more aware of the distinctions and the problems that arise, for example, from hospital discharge.

'First and foremost, the patient's journey is the patient's journey through life; we don't, I think, experience one minute "I'm being a patient and the next minute I'm being a person", much as the system might try and do that by taking my clothes away and putting me into a hospital gown. The journey is the journey of my life; it includes negotiating my way through a territory called disease, but it is part of the larger journey of life.'

Ian Kramer, Expert Patient¹⁷

'If people have more than one condition, they see different specialists, but the consultants never consult together. There is only one person, but consultants give different advice, each one looking at the patient from a different perspective, but not as a whole person.'

Blood Pressure Association

Patients and carers want a truly patient-centred health service

It is apparent that there are concerns about the resources of the health service available to provide specialist care. Once the right consultant or specialist is found, however, the service and the evaluation of it are personalised, and unless there is inadequate financial support for the specialist, patients are much more positive. The size and impersonality of the NHS clearly leaves patient groups cold, and struggling to focus their praise or criticism.

'So few professionals know enough about endometriosis. Even when you are referred to a specialist, you don't see the same person every time, but see different people every time.'

National Endometriosis Society, Cambridge

'Since I've been telling the consultant and GP what I want, things have been better.'

National Endometriosis Society, Cambridge

'Since being referred to a consultant who is an endometriosis specialist, I have been very pleased with the level of care that I have received for my endometriosis. I feel that my consultant works in partnership with me, and knows the downfalls of the system. In addition I have always found him very compassionate and understanding. Of course he does not know what it is like to have endometriosis, he could never know he is not a woman, but his view is that as the patient I need to be able to communicate to him what it is like to live with the disease and therefore what I want out of my healthcare to enable me to live with the disease.'

¹⁷ Source: *Clinical Governance Matters* written by Pip Hardy and Ross Scrivener and published by the UK Health Education Partnership in 2004 <http://www.city.ac.uk/ukhep/>

National Endometriosis Society, Cambridge

'Sometimes I think it's a bit like if you went to the hairdressers and the hairdresser said "well 73% of clients prefer their hair blonde and shoulder length and so that's what you're going to get".

Well, blonde and shoulder length I don't think would particularly suit me. It may well be true that 73% of people want it that way, but my hair is important to me and I'm entitled to a course of treatment that is certainly scientifically medically valid, but it needs to fit into my life as well and not just work in the test tube.'

Ian Kramer, expert patient¹⁸

Patients who have had bad experiences of care divide between those whose problems arose from individual failings by clinicians (such as lack of respect) and those whose problems emanate from a system which doesn't treat patients as people. Individual doctors' fallibility is considered acceptable, but patients consider that more must be done to engage with PCT members on a wider level. Personal care is needed as much as treatment.

'I've rarely been in an NHS environment where I have felt 'cared for'. I don't think you receive care, I think you receive treatment, it's very different.'

Patient with kidney disease and chronic fatigue syndrome

'Hit and run [carer] services are task-oriented but they shouldn't be. They're all private companies now so they are trying to do the jobs as quickly as possible because they're all profit-driven.'

Alzheimers Society

Lack of good time-keeping, or the failure on the part of the PCT to deliver a service, are specifically mentioned.

'Annual reviews for people with diabetes are not routinely carried out on time.'

Diabetes UK, Yorkshire

'Psychiatrists are elusive. They do not want to speak to carers/users individually. [There is a] lack of communication, lack of trust. They need to know their position and be able to listen and be more sympathetic to their patient needs and support the patient and their families if necessary...You often think you are seeing the specialist! You wait for six months and then they don't do anything for you and send you home.'

'Focus on Carers' Conference

'It's not up to the patient to make excuses for the medical staff though. The service either exists or it doesn't. If you're offering the service then do it properly.'

Kidney disease/CFS sufferer

'You can't get an NHS dentist in [the] City – there just isn't one.'

Alzheimers Society

¹⁸ Source: *Clinical Governance Matters* written by Pip Hardy and Ross Scrivener and published by the UK Health Education Partnership in 2004 <http://www.city.ac.uk/ukhep/>

There is a general feeling that making complaints or asking questions is not appreciated, especially from carers rather than patients:

'They don't really want complaints, they just have to show that they've asked you.'

Alzheimers Society

'Patients don't know who to complain to. This doctor doesn't refer you to other people, he just gets irritated.'

African Caribbean Elders

'When they need money, they come knocking on our doors. But when you complain they don't want to know. I want to speak the truth and I'm not ashamed – but everything is swept under the carpet. We don't know what to do if we have a complaint.'

African Caribbean Elders

'Care homes should have independent monitors/inspections. They don't like you asking questions and airing concerns.'

Alzheimers Society

Patients are prepared to accept the fallibility of doctors and the system they operate in and to work to change their style of treatment:

'I think what they need to do is just listen to people – it's not ignorance, it's just a matter of time and sympathy. I think the only way to change anything is to complain. If you don't complain nothing happens.'

National Endometriosis Society, Cambridge

'There's sometimes a lack of subtlety and lack of acceptance that they may be doctors but they don't actually know everything.'

Patient with kidney disease and CFS

'You need a GP that will back you up and refer you.'

National Endometriosis Society, Cambridge

'Of course you can't expect the GP to know everything – they are generalists. They can try to refer you to different people, and while the patient is getting frustrated, the GP is just trying to go through the different possibilities. They do the best they can – they give you an internal exam and explore the possibilities.'

National Endometriosis Society, Cambridge

Patients view consultation, engagement and communication as central to improving the patient experience.

'Users and their carers should have choice, voice and control over what happens to them at each step in their care.'

NHS Cancer Plan London: DH

It's not just information about the condition which patients seek. They want to feel part of the process they are going through by knowing more about the people they are due to meet, the tests they are going to be given, the treatments they may receive and the places they might be able to use, so that they can make informed choices.

'The more information you have about the hospital and the people, the less fearful you are. You need to know who you are going to see, what their specialist skills are and those of their team.'

National Endometriosis Society, Dorchester

'I didn't know there were so many different kinds of homes – nobody told me. Social Services have produced a glossy new brochure, but they are hard to get hold of and not comprehensive at all.'

Alzheimers Society

'I have learnt that it is not just about 'curing' symptoms, it is about quality of life which means thinking carefully about drug treatments, surgery etc and being equipped to ask the right questions of the health professionals so that as a patient you feel you can be involved in managing your own disease.'

National Endometriosis Society, Cambridge branch

'I didn't know that we could get chiropody at home. There needs to be a list of dentists, chiropodists, opticians, who might do home visits or at least who can care for people with dementia – there's a lack of information – they don't tell you what's available.'

Alzheimers Society

'Better communication between doctors and patients could improve standards of care and quality of life for people with asthma.'

Asthma UK

'Clinical Governance should have some sort of lay and user leadership, which would present a powerful message about the purpose of clinical governance. So, if CG committees are meeting, these could be chaired by a lay person or service user. For example, a local Diabetes UK person could chair a group, to provide appropriate focus for patients, rather than just benefiting clinicians. This could help to ensure consistency of standards of service delivery. Even professional development becomes lost...'

Age Concern

However, in order to be able to participate in communication and consultation, patients do need to be able to understand. Information needs to be clear and comprehensible, even for those without any medical training – and it needs to be communicated in the spirit of partnership and collaboration. Trained professional interpreters should be used where necessary and NHS staff should receive training on working with interpreters.

'Family members and friends should not be used as interpreters. If you do not speak the language that they are interpreting into, you will be unlikely to notice any errors that they make. Using a family member or friend to interpret for you

while you are talking to a non-English speaker / deaf / blind person also raises many conflicts. The relative or friend is involved in family or personal dynamics and often has a strong viewpoint, which can interfere with interpretation. You also have no control over the level to which the family member or friend is competent to interpret accurately. They are unlikely to know the specialised vocabulary / terminology you use. For ethical reasons, children should NEVER be used as interpreters.'

Cintra

Special care needs to be taken with people whose best language is not English or who may have particular communication needs, such as patients suffering from aphasia or dementia.

'It's all very well telling us we can have the leaflet translated, but they write that on the inside of the back cover where nobody looks.'

Cintra

Patients regard themselves as people first

The vastness of the NHS, even at a local level makes individual treatment and personal care an almost impossible task. It is the specificity of healthcare which differentiates a good quality experience from one of disenfranchisement. Patients are individuals and their need for personal care is as great as their need for treatment.

'By showing that messages and delivery mechanisms have to be tailored for different groups – e.g. take into account literacy levels, the fact that access isn't just about wheelchairs and stair lifts.'

Diabetes UK Yorkshire

'There's a lack of knowledge about the specialist care of people with dementia.'

Alzheimers Society

'So no one can really help me so I don't really see them as caring for me, I just see them as people who monitor me in a puzzled or expectant way. There is very little emotional 'care' from anyone.'

Patient with kidney disease and chronic fatigue syndrome

'We're looking for more structured education for BME Communities. Funding of videos for BME groups and other tools. Fair and equal care for all with CF irrespective of where they live. Referral to a specialist CF centre. Appropriate care, treatment and drugs funded.'

Cystic Fibrosis Trust

'People with Alzheimers need one-to-one help. They have specialist needs that are all different. There needs to be some kind of central mobile specialist service for dementia patients on any ward, who would come in and look after them – a Short Term Response Unit (!).'

Alzheimers Society

'The future is about teamwork, education and communication. People with diabetes, Diabetes UK and primary care organisations must work together to improve services. Local implementation teams need to incorporate health commissioners as part of their decision-making process.'

Diabetes UK

'Consultants shouldn't be blaming the person, but recognising that the pills don't necessarily work, because they don't suit that person or interact with other meds the person is taking.'

'They forget that they are dealing with human beings, and think that they are dealing with an object. If the object doesn't behave properly, then it must be the fault of the person – must not have taken the meds properly.'

Blood Pressure Association

'Specialists are, by their nature, specialist. This often means they don't see the bigger picture and aren't comfortable with the way their treatment impacts on'

*other illnesses or the rest of your life generally. Some are good, others aren't.
Treat the patient and the illness not just the illness.'*

Patient with kidney disease and chronic fatigue syndrome

'A large part of the population who are seen by the NHS have more than one condition, any one of which may not be curable, but this isn't reflected by the clinicians in the NHS and how they are trained.

Clinicians specialise in one bit, or focus on NICE guidelines on specific conditions. Some treatments would be contra-indicated, so if you have a physical disability and depression, say, they may be related but treatments for one may be contra-indicated by treatments for another. So the issue then becomes one of finding out what is most appropriate within the context of the person's life, enabling them to make the most of their life. So, if someone is having diuretics all the time, they may be frightened to go out for fear of not being able to get to a loo in time....

So divorcing the condition from the rest of the patients' life is no good for anyone.'

Age Concern

6 Education and information for clinicians, carers and patients improve patients' experience of healthcare.

'My best advice to health providers is to think of us as partners. Treat us like partners. Tell us that you need our help too. You might think about setting up training sessions to help staff know how to ask questions that get the best answers. Make sure compassion is part of the training and include us in the training. We can teach along with you. When talking with us, use pictures (those drawn by you are just as good as the fancy ones – even stick figures). Use plain language not medicalese....'

Toni Cordell, Adult Learner and Literacy advocate¹⁹

While lack of funding for research is considered to be a problem by some support groups, and finance for expensive drugs or operations by others, it is educational materials and facilities/activities which are most strongly called for – both for patients/carers and for clinicians.

'An Organisation with A Memory and A First Class Service emphasised the importance of ongoing learning from and through practice:

- *for individuals*
- *for teams*
- *for the individual organisation*
- *for the NHS itself.'*

The Strategic Leadership of Clinical Governance in PCTs

Education and information for clinicians is fundamental:

- about conditions
- about dealing with people

The education of clinicians is seen by patient groups to be central to successful treatment, to a better quality of patient care. This is particularly true for those with less well-understood ailments, and for carers.

Clinical ignorance, both at senior and junior level, is seen as the root of many patient problems – especially when it comes to the special needs of those with particular problems. Education is needed both in relation to particular conditions and for dealing with people.

'Listen to us more. Don't close ranks on us. Allow us to see our files. Answer questions.'

African Caribbean Elders

¹⁹ The National Academies Press <http://fermat.nap.edu/books/0309091179/html/240.html>

'Doctors need communication training so they can give people bad news – or any news.'

Blood Pressure Association

'Too many GPs aren't educated. Take the pill [they say] – that will sort out your periods/bleeding/pain. They fob you off, give you smears, when you are exhausted they will give you anti-depressants, pain killers, contraceptive pills, while you are trying to live your life, without having sex, feeling miserable, etc.'

National Endometriosis Society, Stockport

'We seem to be going round and round, and there isn't any light at the end of the tunnel – not with targets the way they are. So we get back to education – if GPs are more aware of the condition, they might diagnose earlier.'

National Endometriosis Society, Stockport

'Carers who come into people's homes aren't properly trained – they don't lift or move people properly. I know they have NVQs, but they don't know what to do. There's a lack of knowledge about the specialist care of people with dementia.'

Alzheimers Society

'My wife can't walk now after a fall at the Alzheimers Day Centre. An ambulance came for her and I met her at the hospital. Her broken hip was operated on the next day. When I arrived before the operation, her nose was bleeding and she was bruised. I was told she had fallen out of bed – they hadn't even put a rail around the bed, even though I could have told them that she would need to go to the toilet in the night. I don't know how long she lay on the floor after she had fallen.'

Alzheimers Society

'All doctors need to have some course in bedside manner – how to deal with patients – with living, feeling people. Not dummies or robots, or 'interesting cases'. If they did such a course, they would probably find the recovery rate would improve.'

Blood Pressure Association

'There seems to be a significant mis-match between health needs now and health needs in the future in an ageing society, in terms of training, development.

There is a need to recognise that fact as a first step. Then recognise that the training of professionals should be intended to meet the populations' health needs, so then there would be an analysis of these, and of whether training will meet these. Clinicians are not being trained to treat the whole person, they need perhaps to focus less on curing and more on supporting people living with long term conditions (and on avoiding long term conditions in the first place).

So they need to be looking at health and quality of life rather than illness and disease conditions. They need to follow the advice of the Airline that says "Recruit for attitude and train for skill".'

Age Concern

Information enables patients and carers to participate more fully in the process of care.

Patients are much more likely to be distressed and frustrated with their care if they are not *au fait* with their illness. They are ready to become involved with detailed information on their condition in order to better understand their options, and to help clinicians diagnose them.

'The notion of partnership between the healthcare professional and the patient, whereby the patient and the professional meet as equals with different expertise, must be adopted by health care professionals in all parts of the NHS.'

DoH (2001) *Shifting the Balance of Power within the NHS: Securing delivery*

Patients are much more likely to be distressed and frustrated with their care if they are not *au fait* with their illness. They are ready to become involved with detailed information on their condition in order to better understand their options, and to help clinicians diagnose them.

'We need to take responsibility also. We need to learn to ask questions better. I would recommend more training for us. Remember we want to be part of the solution.'

Toni Cordell, Adult Learner and Literacy advocate

Education of patients is seen as a two-level process: the provision of factual guides (literature or seminars) about the specific ailment and its treatment, and personal one-to-one information from the clinician about treatment which is being offered or applied. Self-education through patient/carer groups or from internet research is considered valuable, but is seen as a substitute for something the health service should provide and doesn't.

'I've had good experiences, but only because I've educated myself'. You need to know yourself what's going on inside, so you know how to deal with it.'

National Endometriosis Society, Cambridge

'When they told me the diagnosis, they said they'd found something on my ovaries that might be endometriosis. I was lucky I'd read up on it because they didn't really give me any information.'

National Endometriosis Society, Cambridge

'Whatever the condition is, when you are newly diagnosed, the doctor or nurse should sit down with you and explain what is going on. Over the years, the half hour that it might take will be saved over and over.'

Blood Pressure Association

'A lot of consultants will give you a diagnosis, but then it's up to the patient to find out more about it. The only leaflets around even now are the ones we've left around. It would be quite nice if they could give you some info, and tell you about support that's available. A simple leaflet could tide you over until your follow-up appointment.'

National Endometriosis Society, Dorchester

'Diabetics are told – and are expected - to manage their own condition. However, newly diagnosed people don't know what they can eat or not eat. They received no information at all.'

Blood Pressure Association

'It depends on how eloquent or articulate the patient is – I am a nurse and managed to have children, with a few fertility problems, but I think it is just because I am a nurse that my route through healthcare has gone quite smoothly – I'm informed and confident and competent and diagnosed myself.'

National Endometriosis Society, Dorchester

'We need information we can understand on paper, plus we need someone to speak to us. It's important to know what affects you the most so we can guard against it. You need to go to the barbers and churches so everybody knows what's going on and people can be protected early.'

Lewisham Community Development Partnership

'I went along with some notes and questions (because I also have dyslexia, so I write everything down to save doctor's valuable time) but the nurse was horrified! I think she was frightened that she might not know the answers!?'

Blood Pressure Association

'The primary care sector is very naive to the needs and wants of a person with CF, this inhibits their quality of care. Improvement would be for them to have a basic understanding of what is normal procedure for a person with CF.'

Cystic Fibrosis Expert Patient Advisor

'A lot of consultants will give you a diagnosis, but then it's up to the patient to find out more about it.'

National Endometriosis Society, Dorchester

'In 1995 it took an average of seven years to get a diagnosis. It now takes an average of nine years.'

National Endometriosis Society, Stockport

'More and clearer information to patients. Best practice should be shared.'

Blood Pressure Association

'Of course, it's women who are informed that come to support groups – what about all the women who don't know enough to find out about what support is available?'

National Endometriosis Society, Dorchester

'I had high blood pressure but I read information in the doctor's surgery in a leaflet, because the doctor didn't tell me much or give me much information. I went to the library and read some books about it, then my blood pressure went down because I stopped taking salt in my diet.'

Lewisham Community Development Partnership

Support groups/voluntary organisations see their role as central in education.

Voluntary organisations would like to provide education for NHS staff as well as for their members, patients and carers, in order to promote more effective partnership working to improve the quality of care. However, attempts at education are often ignored.

'The way forward is training, education, awareness – for doctors and carers and clinicians – and funding for it.'

Alzheimers Society

'The only leaflets around even now are the ones we've left around. It would be quite nice if they could give you some info, and tell you about support that's available. A simple leaflet could tide you over until your follow-up appointment.'

National Endometriosis Society, Dorchester

'Whenever a child is diagnosed with MPS, we send information leaflets to their GP's surgery. But often the doctors don't even bother to read them.'

MPS Society

'If there isn't time for the GP to talk to you, they should send you to the BPA, or relevant organisations. So GPs ought to know where to find the information.'

Blood Pressure Association

'Back to old-fashioned days of GP service where they knew patients, and there was continuity of care, where the doctor was interested in finding out about the disease because he has a patient with the disease. Some doctors aren't even interested when MPS Society offers help and info, e.g. there is deliberate targeting of surgeries where a patient has MPS, and the society sends out information leaflets when a child is diagnosed.'

MPS Society

'There needs to be more education of GPs so they are more aware of it. Every GP can diagnose appendicitis, but they should know enough about endo to at least suspect it. They should know the right questions to ask. There could also be seminars (organised by PCT) with attendance from at least one GP from each practice. Then they could go back and pass on information to others in the practice, so they could realise that they aren't asking the right questions, or missing symptoms.'

National Endometriosis Society, Dorchester

GOOD PRACTICE CASE STUDIES

Case study 1: Health of Man

In Bradford, a radical approach has been taken to health care for men. At Shafiq Ahmed's barbershop, customers can have a regular health check from North Bradford Primary Care Trust (PCT) staff, who visit the shop weekly to advise on health issues and offer services such as blood pressure, glucose and cholesterol checks. Not only is the barber's shop in an unconventional location, but it's in a part of town that caters primarily to the largely Asian local population.

The initiative is just one of a number of imaginative schemes introduced by a special project designed to promote men's health to Asians in Bradford, West Yorkshire. The Health of Men (HOM) project, which has brought together four PCTs and a number of other diverse partner organisations, has just embarked on the second year of a five-year plan to promote men's health across the Bradford and Airedale district.

In a report published in 2004, what is believed to be the first in-depth scrutiny of healthcare in non-traditional settings such as mosques, barbershops, football tournaments and prisons, as well as pubs, it is estimated that up to 15 per cent of the men who attended pub clinics in the Bradford and Airedale district were referred onto doctors due to previously undiagnosed problems.

Posters are put up a couple of weeks beforehand to get customers used to the idea, then during the clinics they are offered a wide variety of tests, including blood pressure, cholesterol and weight.

'We talk about lots of topics, anything from diet, exercise, giving up smoking and mental health to prostate and testicular cancer,' said community nurse Phil Arnold. HOM also runs pub quizzes as a way of providing health-related information to punters.

Landlord Kevin Hodgson of The Royal pub, said: 'I was the most sceptical of everyone at first, but the nurses have actually brought more customers in.' The report also highlights the success of a health 'fair' at Hull prison, featuring the condom demonstrator and rubber testicles!

The clinics that Arnold started have now doubled in size and the HOM network would like to see the idea extended across the rest of the country.

Sources: *The Big Issue*, March 15-21 2004. p.6

http://www.menshealthforum.org.uk/uploaded_files/HOMreport03.pdf

David Moss-Blundell http://www.menshealthforum.org.uk/userpage1.cfm?item_id=1260

www.healthofmen.com/ offers up-to-the-minute, friendly advice in an accessible fashion.

Case study 2: A humane gesture

'One of the nicest things that ever happened to me was when a consultant that I had, I was perched on the examination couch and she'd make a habit of simply taking my hand while we talked. And that gesture, that intimate and humane gesture, that gesture of saying "I'm a person and I understand that you're a person" moved me very greatly and I also think contributed to the quality of care, because it brought into balance the intimacy of the clinical relationship with an intimate personal relationship and made me feel much more comfortable.

I don't know whether it was because she was a woman doctor or just because she's a good doctor, but that gentleness and humanity of touch meant a great deal to me at the time and still does. And to the extent that it doesn't necessarily have to be done by holding the patient's hand, and perhaps not every patient would be comfortable having their hand held, but that establishment of an emotional contact was very, very important.'

Ian Kramer, Expert Patient

Case study 3: Lindsay Leg Clubs

The Leg Club meets every Tuesday afternoon in the local community centre. Members come even after their leg ulcers are healed, for a cup of tea and a chat and a check by the multi-skilled team of nurses who are there to change bandages, dress ulcers, check blood pressure, administer Doppler tests and generally keep tabs on members who are encouraged to come regularly as part of the 'well leg scheme'. Varicose veins, eczema, difficulties with walking and other leg-related problems, together with the isolation, loneliness, pain and immobility that often accompany these conditions, can also be treated.

The secretary, who has only missed one Tuesday in five years, brings sandwiches and cakes that she has made; the money for the rent for the village hall is raised by a weekly raffle of items brought by members, all to a pleasant background of music provided by a cassette.

Data kept by Lindsay Leg Clubs indicates that leg ulcers heal more quickly and patients remain healthier following this social model of care, where relationships are formed and the nurses actually get to know the patients as people. In a friendly and supportive environment, members are exposed to positive health beliefs and encouraged to share responsibility for their condition. The resulting improved concordance with treatment also leads to better general health and well-being and, not surprisingly, results in significant savings over treatments provided via more traditional leg ulcer clinics or home visits.

The nurses work as a closely-knit, passionately committed team, believe that they make a real difference, through patient empowerment and true collaborative working.

www.legclub.org

Case study 4: Harrogate Carers' Resource Centre

The Carers' Resource Centre in Harrogate prides itself on its 'versatile and highly experienced team which has developed considerable insight into the specialist nature of carer support and into ways in which health and social care can benefit from services such as ours, to the advantage of carers, users and the delivery of community care'.

In a pleasant Victorian house in a tree-lined avenue in Harrogate, The Carers' Resource does exactly what it says on the tin: it provides resources – and support – for carers. Staff work closely with GPs and other healthcare professionals, as well as schools, to identify people who can benefit from their services, and there are now some 5,000 carers (including young carers) making good use of the wide range of specialist and generalist services on offer. While the primary focus is on the needs of carers and the provision of

- appropriate and relevant education and training,
- information and advice and,
- most importantly, listening and emotional support,

professional support is also offered to health and social care staff to help meet quality standards and develop and deliver appropriate services for carers.

"They sent information and invited us to drop in any time for help or a chat. They are so understanding and aware of our concerns; always prepared to listen and to help. When Eric was in hospital, they became a lifeline. Anne even telephoned in the evenings to offer support." Greta and Eric Guymer on DH website

The Carers' Resource Centre is part of the Princess Royal Trust for Carers network of 122 independently managed carers' centres. These centres provide quality information, advice and support services to 180,000 carers, including 10,300 young carers throughout the UK.

'Almost every Carers' Centre is structured as an independent charity and is a partnership with The Princess Royal Trust for Carers and statutory authorities. This allows each Carers' Centre to deliver a wide range of local support, which meets the needs of carers in their own communities whilst also contributing to and benefiting from the support of a national framework. This Carers' Centre model is capable of being adapted throughout the UK.'

Carers' Resource, Harrogate www.carers.org/local/north-east/harrogate/

Princess Royal Trust for Carers www.carers.org/

OVERALL LESSONS FROM OUR CONSULTATION WITH PATIENT AND CARER SUPPORT GROUPS

Patients, carers and support groups would like to see improvements in the quality of care they receive, but aren't all expecting miracle cures, ground-breaking surgical developments or ultra-efficient services. They would like:

- greater recognition of the key role played by carers
- better clinician education on specific ailments
- greater involvement and participation in working groups and decision-making in PCTs. This includes two-way communication about specific changes in the care facilities, education events and materials, which the support organisations feel they can help with,
- more respect and consideration in their care from clinicians, especially consultants and doctors. This will emanate from both better understanding of the specific conditions, and some sort of education in people skills
- care that acknowledges patients as people and individuals
- participation by specialists in the patient groups. Where consultants have become involved in group meetings, mutual respect and understanding has resulted
- more patient education and clarification of the process so that patients know what to expect (even if it isn't enough).

'Although most of our experiences are good, it's the bad ones that stick in our minds, because we have an emotional response to them. It is our feelings that govern our attitude to our patient experiences.'

Quality Dashboard participant

Voluntary support groups can offer a good support service and specialist information for patients and carers which the general health services aren't providing at the moment.

'By co-operation we could supplement their service provision – we would not replace their provision they're obliged to provide. We could, if we had been involved in projects, promote them amongst our membership and possibly include our name and support on promotional literature.'

Diabetes UK London

'Wider public consultation. Development of user groups and respective focus groups.'

Diabetes UK

'Development of clear knowledge and subsequent guidelines for patients – what care to expect. Consistent culturally receptive patient education tools.'

Diabetes UK

'Build on and share best practice across the country to ensure equity of services to carers. Change name; take away the medical poignancy, make it more user/carer friendly and focused. Carers need to be recognised, identified and have access to support and assessment equally across the country.'

Princess Royal Trust for Carers

'They could listen to people who use the service and make changes accordingly so that everyone gets what they need when they need it in an appropriate setting.'

Diabetes UK, Yorkshire

'If PCTs facilitated choice by enabling patients to go to their preferred CF centre more readily than they do at the present, access would be improved.'

'Provision of suitable literature – disseminate projects procedural changes through our local groups involving our local groups directly with their PCT.'

Diabetes UK, London

'We need protection from abuse of professionals. Setting carers up as emotional/ nuisance to get them banned. Carers need to be respected. Heard more especially when looking after a very sick person & GP's need to have a more of a liaison (one to one) approach as he or she would do with a nurse or reception.'

'Focus on Carers' Conference

Appendix 1: List of voluntary organisations and their membership

Organisation	Number of members	Number of patients represented	Number of carers represented	Responded to questionnaire	Provided research	Conversation with an official	Met with members
African Caribbean Elders (Kilburn)				[Not sent]	-	Yes	Yes
Age Concern www.ageconcern.org.uk				-	-	Yes	
Alzheimers Society www.alzheimers.org.uk		750,000 (est)		-	-	Yes	Yes
Arthritis Care www.arthritiscare.org.uk				-	-	-	-
Asthma UK www.asthma.org.uk	10,000	5.2 million	1 household in 5 has at least one person with asthma	Yes	From website	-	-
Blood Pressure Association www.bpassoc.org.uk					-	-	Yes
Carers UK www.carersuk.org/	8,000 individuals, 700 organisations	6 million	500,000 (est) in reality 6 million carers	Yes	Yes	Yes	Yes
Cintra www.cintra.org.uk	750 interpreters	Constantly changing!		-	-	Yes	-
Cystic Fibrosis Trust www.cftrust.org.uk	No members	7.500	15,000	Yes	yes	-	email
Diabetes UK West Midlands www.diabetes.org.uk/	180,000	1.8 million	1.5 million	Yes	-	-	-
Diabetes UK Northern and Yorkshire	170,000	2 million + the missing million	?	Yes	-	-	-
Diabetes UK Northwest	190,000	3 million	3 million	Yes	-	-	-
Diabetes UK East Midlands	4,000-6,000 regionally	138,000 regionally	?	Yes	-	-	-
Diabetes UK London	180,000	173,000	6,500	Yes	-	-	-
Help the Hospices				(Bolton Hospice)	-	-	-
Lindsay Leg Club Foundation www.legclub.org	14 Leg Clubs (3 more to open late 2005)	>1.400 million		Yes	Yes	Yes	Yes

MPS Society www.mpssociety.co.uk	2,400	1,200	2,400	Yes	-	Yes	Yes
National Endometriosis Society www.endo.org.uk/	2,500	2 million	Difficult to answer	Yes	Yes	Yes	Yes
National Osteoporosis Society www.nos.org.uk/	24,000	3 million	-	Yes	-	-	-
Princess Royal Trust for Carers www.carers.org/	122 centres, 240,000 carers via network		c. 6 million carers	Yes	Yes	Yes	Yes