



'Getting over the wall'

How the NHS is improving the patient's experience

DH Information Reader Box

Policy	Estates
HR/Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership

Document Purpose Best Practice Guidance

ROCR Ref: **Gateway Ref:** 3817

Title 'Getting over the wall' How the NHS is improving the patient's experience

Author Meredith Vivian, PPI Workstream, DH

Publication Date 1st October 2004

Target Audience PCT CEs, NHS Trusts CEs, SHA CEs, Care Trusts CEs, WDC CEs, Directors of Nursing, Copied to NHS Foundation Trusts for information

Circulation List

Description An illustrative document providing examples of how the outputs from patient and public involvement activity have influenced service planning and development in the NHS to deliver improvements for patients.

Cross Ref Strengthening Accountability

Superseded Docs N/A

Action Required N/A

Timing N/A

Contact Details Meredith Vivian
PPI Workstream
Room 608
Richmond House
79 Whitehall, London SW1A 2NS
020 7210 5043

For Recipient's Use

'Getting over the wall'

How the NHS is improving the patient's experience

Contents page

The build up to ‘Getting over the wall’	4
The NHS Plan	4
Section 11 of the Health and Social Care Act 2001	5
Choice, Equity and Responsiveness	5
Building on the Best	6
The Commission for Health Improvement – Findings about PPI activity	6
Patient and Public Involvement in Health: The Evidence for Policy Implementation	7
The NHS Improvement Plan Public Service Agreement (PSA)	8
‘Getting over the wall’ – shifting the focus of patient and public involvement activity	9
What needs to happen	9
What NHS organisations need to do to achieve this	11
How they scaled the wall – the NHS tells its story	13
Chronic conditions – Osteoporosis Dartford, Gravesham and Swanley Primary Care Trust	14
Delivering a service user charter for people with learning difficulties Brent Primary Care Trust	16
Making a difference in a specialist learning disability trust Calderstones NHS Trust	18
Maternity services – Focus groups Helston Birthing Unit West of Cornwall Primary Care Trust	20
Mental health – User Focused Monitoring Kensington and Chelsea Primary Care Trust and Westminster Primary Care Trust	21
Mental health services – A view from the ward South London and Maudsley Mental Health NHS Trust	22

Neurosciences Centre – Patients’ panel Hammersmith Hospitals NHS Trust	23
Older people – Patients’ stories Cherrydown Ward, Basildon Mental Health Unit South Essex Partnership NHS Trust	25
Orthopaedic, Gynaecology and Urology Nottingham City Hospital	26
“Our services can be better than this” Looking for ways to improve outpatient services Morecambe Bay NHS Hospitals Trust	28
Paediatric physiotherapy group Dartford, Gravesham and Swanley Primary Care Trust	30
People with long-term conditions – Involving PALS Taunton Deane Primary Care Trust	32
Phlebotomy services Press release Cheltenham and Tewkesbury Primary Care Trust	33
Primary care – Proposed closure of a branch surgery in Eccles PALS support in the community Maidstone Weald Primary Care Trust	34
Sexual health clinic – Patients’ network Camden Primary Care Trust	36
Strokewatch – A local stroke survivor group Hull and East Riding Stroke Service	38
Sure Start Spa Spiders Family Planning Service Doncaster West Primary Care Trust	40
‘The little things are important’ – Exit cards Taunton and Somerset NHS Trust	42
‘Time to talk!’ East Somerset NHS Trust	44

Welcome evenings Sussex Cancer Centre	45
Working with travellers in St Day West of Cornwall Primary Care Trust	47
The importance of using appropriate language Examples of unintentional gaffes	48
References	49
Acknowledgements	50

The build up to 'Getting over the wall'

There are a number of historical and important drivers that provide the background for this document. These are set out below. One of the most significant is the Commission for Health Improvement's report, Involvement to Improvement, produced in February 2004. This report highlights what the Commission had learnt about patient and public involvement work and talks about there being a brick wall between the patient and public involvement activities and any changes being made to health services.

The purpose of 'Getting over the wall' is to help the NHS to shift the focus of its patient and public involvement work from activity - **process** - to **outputs** and **outcomes**. In this way it will be able to get over or demolish the wall described by the Commission for Health Improvement. Patient and public involvement (PPI) needs to be part of everyday practice and **involvement must lead to improvement**. Only then will patients have a greater say in the way the NHS is planned and developed, and their experiences improve.

The NHS Plan, July 2000

The NHS Plan provides the model for delivering a health service for the 21st century, with services designed around the needs of patients and improved health, particularly for the poorest people in our society.

A set of core principles underpins the plan. These include the following.

'The NHS of the 21st century must be responsive to the needs of different groups and individuals within society, and challenge discrimination on the grounds of age, gender, ethnicity, religion, disability and sexuality. The NHS will treat patients as individuals, with respect for their dignity. Patients and citizens will have a greater say in the NHS, and the provision of services will be centred on patients' needs.'

Link www.dh.gov.uk

Section 11 of the Health and Social Care Act, 2001

Section 11 of the Health and Social Care Act 2001 places a legal duty on the NHS to involve and consult patients and the public in the planning and development of health services and in making decisions that affect the way those services operate.

This duty has been a legal requirement since January 2003. In February of that year the Department of Health published the policy and practice guidance, **Strengthening Accountability**, to help the NHS to carry out the new duty.

' 'Involving and consulting' has a particular meaning in the context of Section 11. It means discussing with patients and the public their ideas, your plans, their experiences, why services need to change, what they want from services, how to make the best use of resources and so on. It is more about changing attitudes within the NHS and the way the NHS works than laying down rules for procedures.'

[Link www.dh.gov.uk](http://www.dh.gov.uk)

Choice, Equity and Responsiveness

In Autumn 2003 the Department of Health launched Choice, Equity and Responsiveness, a national consultation to give staff, patients and the public an opportunity to tell the Government what choices they would like to be able to make about their health and health services. The consultation was also known as 'Fair for all, personal to you'.

'Choice is a core principle of the government's approach to making public services more customer focused.'

'Designing services around the wishes and choices of different groups of patients will improve access to care and treatment and reduce health inequalities.'

[Link www.dh.gov.uk](http://www.dh.gov.uk)

Building on the Best

The document, Building on the Best, summarises the responses from the Choice, Equity and Responsiveness consultation. There are several themes that appear frequently. These include the following.

About patients

- 'Our health needs are personal, and we would like services to be shaped around our needs, instead of us being expected to fit the system.'

'What the NHS needs to do'

- 'Listen to what patients and the public are telling us and then act.'

Link www.dh.gov.uk

The Commission for Health Improvement Findings about patient and public involvement activity

In February 2004 the Commission for Health Improvement produced a report describing what it had found out about patient and public involvement (PPI) from more than 300 inspections of NHS organisations and from its own research into the topic. This report, called 'Involvement to Improvement, i2i', included the following statements.

'Organisations are getting better at some aspects of PPI

The NHS is, on the whole, improving in some aspects of PPI, such as providing information for patients and undertaking qualitative and quantitative exercises in getting feedback from patients. But it is not doing as much to ensure that patients, carers, service users and the public influence decision making.'

'PPI is not part of everyday practice

Pockets of good practice are not being shared across organisations or being picked up at strategic level. Organisations are failing to integrate PPI activities with other efforts to improve services and are not making PPI central to core activities.'

'Involvement is not leading to improvement

PPI is not yet having a major impact on policy and practice. This is despite a plethora of PPI initiatives. **It is almost as if there is a brick wall between the activities going on and any changes on the ground that happen as a result.'**

Link www.healthcarecommission.org.uk

Patient and Public Involvement in Health: The Evidence for Policy Implementation

In 1999 the Department of Health commissioned the Health in Partnership programme. This was a programme of 12 research projects, each exploring different areas of patient and public involvement in health. The aim was to shape policy and practice throughout the NHS.

Patient and Public Involvement in Health: The Evidence for Policy Implementation was published in May 2004 as a summary of the results of this Health in Partnership research programme. The findings of the report contribute in an important way to the growing body of evidence that demonstrates the benefits of patient and public involvement. The report makes the case for greater involvement and offers an insight into the practice of involving people at different levels. Some of the findings are set out below.

Patient involvement

'Patients feel involved in their care when they are treated as equal partners, listened to and properly informed. Privacy and time for discussion are both required to achieve this.'

'Benefits include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects.'

Public involvement

'Leadership, board commitment and inclusion in strategic planning are all important for the success of public involvement, which should be a shared corporate responsibility.'

'For any member of staff, gaining confidence and skills in involvement work requires experience of the benefits of involvement and training and education in the methods of involvement.'

Link www.healthinpartnership.org

The NHS Improvement Plan

The NHS Improvement Plan: Putting People at the Heart of Public Services was launched in June 2004. It sets out the priorities for the NHS between now and 2008. It also supports the Government's continuing commitment to a 10-year process of reform first set out in the NHS Plan in July 2000.

It includes the following statements.

'The next stage in the NHS's journey is to ensure that a drive for responsiveness, convenient and personalised services takes root across the whole NHS and for all patients.'

'As money, control and responsibility are handed over to local health services, the communities that they serve will be given greater influence over the way that local resources are spent and the way that local services are run.'

'A new spirit of innovation has emerged, centred on improving the personal experience of patients as individuals, and this is now taking root in the NHS.'

'The NHS is set to thrive by meeting the needs of patients and the public.'

Link www.dh.gov.uk

Public Service Agreement (PSA)

PSA 5 is the current (2003 to 2006) target for improving the patients' health care experience.

'Enhance accountability to patients and the public and secure sustained national improvements in patient experience as measured by independently validated surveys.'

For 2005 to 2008 the PSA target is as follows.

'Secure sustained national improvements in NHS patient experience by 2008, as measured by independently validated surveys, ensuring that individuals are fully involved in decisions about their healthcare, including choice of provider.'

Link www.hm-treasury.gov.uk

To create an NHS that can deliver the kind of service which staff, patients and the public said they wanted in the Choice consultation will mean the NHS has to listen to what patients are telling it and act. Only then will patients have a stronger voice.

So what does the NHS need to do to demolish 'the wall' or make sure it doesn't get stuck behind it?

'Getting over the wall' – shifting the focus of patient and public involvement activity

What needs to happen

CHI reported its three key findings about PPI activity. It talked of there appearing to be a brick wall between PPI activity and any changes being made to health services.

This means that what patients and the public said during involvement activities – the **outputs** from involvement exercises, - is not really influencing the **outcomes** of the NHS's decision-making processes to change and improve services.

After all, what is the point of involving patients and the public if organisations are not prepared to listen and respond to what they say? The following example illustrates behaviour that is common in many NHS organisations. The organisations remain anonymous but the example is fact.

Three PCTs prepared a joint business case for a Local Improvement Finance Trust (LIFT) bid. Two pages of the document were devoted to the consultation process – these were lists of who the PCTs had met with; where and when the meetings had happened and who attended them from the PCTs.

However, the PCTs did not say what the **outputs** from the consultation meetings were – in other words, what people said at the meetings, nor did the business case show any evidence that it had been influenced by what people had said. There was no **outcome** – the PCTs were stuck at the **process** stage behind the brick wall.

How many NHS organisations have been, or are, guilty of doing the same thing – getting stuck at the process stage? It is this type of behaviour that has led to the building of the brick wall. Whilst the NHS is stuck behind it, it is not fulfilling its duty under section 11 of the Health and Social Care Act 2001. What it is doing is merely ticking the box, which means that:

- patient and public involvement is not becoming part of everyday practice;
- it cannot be central to an organisation's core activities; and
- the aims for the NHS set out in the Improvement Plan will be difficult to achieve.

NHS organisations that are regularly involving patients and the public now need to shift the focus of their work to concentrate on the outputs from these involvement activities. In particular they need to consider how the organisation listens and how it is going to respond to the contributions. When this behaviour becomes part of everyday practice, there will be a responsive NHS, providing services to:

- communities that have greater influence over the way local resources are being spent; and
- patients who have more say in their own care.



Harry Cayton, Director for Patients and the Public at the Department of Health emphasises that effective patient or public involvement depends on establishing a clear purpose and using appropriate methods. He stresses the need to recognise the importance of:

- the knowledge that patients and the public bring to the process; and
- sharing information between decision-makers and the public.

Too often those that take part feel they are being 'done to' rather than involved. They feel there is a hidden agenda, that information is being withheld and that decisions have already been made.

The NHS should understand that people taking part in involvement and consultation activities need to be treated as partners. The NHS needs to:

- recognise their knowledge and experience;
- make sure the objectives of the involvement activity are clear;
- share information with patients and the public; and
- decide how best to communicate with them before, during and after the process.

None of this is difficult, but in the end patients and the public will only have a reason to take part if the NHS truly intends to involve them and change what it does as a result.

What NHS organisations need to do to achieve this

- Understand the different involvement and consultation requirements set out in section 7 and section 11 of the Health and Social Care Act, 2001 and how these link together.

Link Strengthening Accountability Overview and scrutiny of health – guidance

- Be clear about the role non-executive directors have in relation to the PPI agenda. (They are not PPI ‘champions’ and do not lead on the agenda. At board meetings they must make sure that there are structures in place, and that the board is getting all the information it needs to monitor progress. Non-executive directors do not ‘represent’ the public. They are there to govern the organisation, by using their experiences in other fields and as residents in the areas they serve.)
- Understand that PPI is everyone’s responsibility.
- Always consider the outputs from PPI activities when making decisions about planning and improving services.
- Make sure that PPI is not considered an ‘add on’ or as a separate agenda.
- Demonstrate how patient and public involvement makes a difference to the organisation’s decision-making processes. (How the **outputs** have influenced the **outcomes**.)
- Understand that small changes made as a result of what patients and the public have said are as important to improving the patient’s experience as major service redesigns.
- Build on and celebrate small successes.
- Be aware of the language used - see examples of unintentional gaffes.
- Make choices real for patients. (Without involving patients in setting up and delivering choice locally, the NHS will simply swap one NHS-focused system for another.)

The Department of Health is frequently asked for examples of good practice. The examples included in this document show how some NHS organisations have ‘got over the wall’. All NHS organisations need to be able to demonstrate this in all areas of their work.





How they scaled the wall –
the NHS tells its story

Chronic conditions

Osteoporosis

Dartford, Gravesham and Swanley Primary Care Trust

The Dartford, Gravesham and Swanley PCT area includes Kent Thameside which is part of the Thames Gateway and one of the largest growth areas in Europe. The area is currently undergoing major change and there are major developments in employment, housing and health projects.

As part of the **Choice** project we targeted several areas of chronic disease to see what choices patients with these conditions would like. One of the areas we chose was osteoporosis.

We held a number of meetings with people with osteoporosis, including a reference day with patients and clinicians from the community and the local acute trust. These meetings led to the start of a multi-professional project group that includes two people with osteoporosis and a carer. The group meets every two months to:

- explore service improvements and education programmes that can benefit people with osteoporosis; and
- raise awareness of how to prevent, identify and treat osteoporosis.

The group receives support from a local GP, a local rheumatologist and directors from the PCT.

The project group and members of the Choice team have been working with clinicians to develop the service and improve their knowledge of osteoporosis. Service improvements include the following.

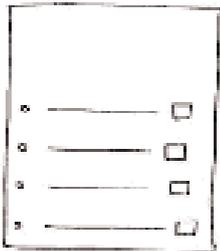
- A scanner for patients who have been referred for bone density measurement is to be provided at the local hospital. (In the past patients have had to travel out of the area for their scans.)
- Several GP practices have agreed to be part of an audit project. An osteoporosis nurse will work with these practices to find patients who are at high risk of osteoporosis. These patients will be called in and will receive the correct diagnostic tests and treatment. The plan is for the nurse to train staff in each practice to carry on this process after the end of the project.
- A screening tool for people who have fallen is being developed to help with assessments and to provide the right treatment for osteoporosis. A variety of professionals and organisations will be involved in this scheme.
- The local rheumatologist and local gerontologist are working on a joint assessment tool for falls and osteoporosis. They are also working on better communication between the A&E department, the orthopaedic ward and GPs for patients who have fallen or had fractures.

- 
- We have distributed posters and information about osteoporosis to relevant wards and clinics at the local hospital.
 - More information will be available on osteoporosis. Staff will be able to access this information on the intranet. Patients will be able to find it on the Kent and Medway internet site. This information will include dietary and exercise information from relevant primary care staff at the PCT.
 - We have organised Healthy Lifestyle Days in local supermarkets and on the community bus and Celebration of Age Days, which are multi-cultural days.
 - The local hospital physiotherapist offers hydrotherapy sessions for patients who have been diagnosed with osteoporosis. The physiotherapist at these sessions accepts referrals from GPs.

Delivering a service user charter for people with learning difficulties

Brent Primary Care Trust

The process



The Government White Paper, 'Valuing People', sets a target for a 'multi-agency quality assurance framework for learning disability services'. In Brent, we wanted to start with the opinions of users, so we set up a local user group of 15 people with learning disabilities who were attending local day centres. The group was called 'Quality Action'.

The first discussions covered the subject of 'What's important about services?'. People looked at four main areas (buildings, staff, things to do and food and drink). Following these discussions user-led focus groups were held in five local disability services.

This generated a series of local standards that defined users' expectations about services. The local partnership board (the decision-making body for local services) agreed to these standards and the PCT's commissioner uses them to monitor the performance of services.

Link to the local plan



The outcome of this process helped us to deliver a national target.

How we involved service users



The Quality Action Group consisted of people with learning disabilities who had ideas about how services should change. Many members of the group had communication difficulties and most did not read, so sessions were recorded visually. This was done, for example, by:

- plotting on a map of Brent the services people used;
- using photos to identify the members of the group;
- recording the minutes of each meeting in 'easy-to-read' format with pictures and symbols; and
- producing a video about the group's work for those who do not read.

We produced the final charter with short statements and pictures to represent each statement.

Outcomes



The partnership board has approved the service user charter. It is now part of the local commissioner's conditions for monitoring performance.

Evidence of the change



There has been feedback from the local people and the organisations involved. We hope to see results as the commissioner uses the charter to monitor services.

Making a difference in a specialist learning disability trust

Calderstones NHS Trust

Calderstones NHS Trust is a specialist learning disabilities trust in North West England. It provides long-stay services that include a range of medium-secure places for offenders with learning disabilities and others with similar needs.

During the **Choice** consultation we arranged a series of discussion groups for clients so that we could include their views in our response.

We have found these opinions very useful, and consider and include them in our development plans where possible.

We have made the following changes as a result of what users have requested.

More Information

Providing more information for clients and their families through various methods already available.

We have used:

- the client's monthly brief;
- the relatives' newsletter;
- a revised version of 'Our services to you' on DVD; and
- day service information and awareness sessions for clients.

Planned care

We are improving access to acute hospital services for our users. Modern matrons and nursing staff at the local general hospital are developing a new access procedure to make sure that outpatients, A&E and admission processes are as helpful as possible for all involved.

Ward and day service user groups and the Patient Advice and Liaison Service (PALS)

Because of the requirements of clinical governance, we already have quality groups in place on the wards. We reviewed the aim of these groups and decided that the PALS could develop them further by widening the range of topics discussed. This means that clients' views and ideas can influence service development in all parts of the trust.

Each user group has a facilitator who is responsible for running the group. This is a nominated member of the ward staff. The facilitator is part of a network of facilitators across the trust



that meets every two months with the PALS officer. The ward clinical team and the modern matron support them.

Are they making a difference?

From the start of the project we realised we needed to establish a strong system of regular meetings, effective communication and responsive feedback before we could start to assess the difference the groups were making. These groups started in July 2003. These are the service changes made so far.

Decoration

Clients said they would like to help choose the colour schemes when their flat is decorated. The Facilities Department is going to let ward staff know in plenty of time when wards are going to be decorated. This will give clients the chance to be involved in helping staff choose the colour schemes for the wards.

How I spend my day (and day services)

From views about day services and discussions on 'how I spend my day' we realised that day services, hobbies and keeping busy are very important to clients. Clients' suggestions have prompted a review of day service activities. Our Chief Executive chairs the review. The suggestions clients have made will help shape our development plans for day services and other activities for clients.

Finance and money

The Director of Finance and Information asked the user group for their views and ideas on how we manage clients' finances.

Several actions came from the feedback received. These included:

- an information leaflet giving general information about bank accounts and benefits;
- an information leaflet about the support which staff will give to clients to help them manage their money; and
- developing workplace training for nurses on how to provide clients with finance and money support.

These developments will be available to clients in September 2004.

Encouraging clients to take part

Taking part in user groups has helped clients to realise that their views will make a difference. This has been reflected in the number of clients taking an active part in the Commission for Patient and Public Involvement in Health's PPI Forum at Calderstones NHS Trust.



Maternity services

Focus groups

Helston Birthing Unit West of Cornwall Primary Care Trust

We held two focus groups with young mothers. Fifteen mothers took part in the groups. The mothers' views at these meetings had a major influence on the way we designed a new birthing unit. A Public Health Scientist project managed the development of the unit, working closely with local midwives.

We provided a crèche to support the first group of mothers. These mothers were part of a peer support group to help them back into education. Two of the mothers were living in hostel accommodation.

This group explored what is important to young mothers in low-tech birthing facilities. The mothers valued:

- the opportunity for more personal care;
- the chance to receive care from local midwives; and
- the fact that the local unit would be more like a home-from-home environment.

The young mothers also felt their present homes would not be suitable for a home birth – for example, because they may disturb the neighbours.

The second focus group was held with local mothers who had given birth in the last two years. This group looked at what features would be important to local people in the new unit. Feedback included:

- a water-birth facility;
- the need for parking; and
- the opportunity to have more control of the lighting.

The outcome

Helston Birthing Unit opened in September 2003 with parking and water-birth facilities.



Mental health

User-Focused Monitoring

Kensington and Chelsea Primary Care Trust and Westminster Primary Care Trust

User-Focused Monitoring (UFM) is a way of assessing services that puts service users at the heart of the process. At the PCTs, the UFM project manager trains and supports mental health users to become interviewers and site visitors. This means that service users can monitor and evaluate the inpatient and community mental health services that we commission.

Using interview schedules developed by service users, the UFM user teams carry out interviews with people in the community who are on enhanced Care Programme Approach (CPA). They also visit inpatient units to find out the views and experiences of service users with severe long-term mental ill-health. UFM is the main quality and performance management tool for assessing our mental health services.

Aims

User-Focused Monitoring has four main aims. These are to:

- give a voice to people with severe long-term mental ill-health and help them to improve services;
- recognise and encourage 'experts by experience' and make sure they guide the process;
- gather information that may be overlooked by or not revealed to non-service user interviewers; and
- provide ongoing user-led monitoring of mental health services.

Outcomes

UFM has had an important effect on mental health services in Kensington, Chelsea and Westminster. It has:

- contributed to the updated CPA policy for the trust;
- provided interviewers who can co-present the CPA training for all community mental health teams;
- highlighted the need for a CPA information leaflet for service users which has been produced in partnership with local service user groups;
- improved the physical environment and information available on all wards and in day hospitals;
- helped to establish 'medication education' groups in mental health units; and
- recommended that kitchens on acute wards should be open 24 hours a day.

The UFM team continues to meet regularly with service managers to make sure their recommendations are being carried out and that improvements are happening.



Mental health services

A view from the ward

South London and Maudsley Mental Health NHS Trust

In August 2000 staff from Lewisham Mental Health Services asked service-user link workers to help them with a process to review inpatient care. This has now become a much larger project that takes place in community teams as well as in inpatient wards, and involves a wide range of service-user link workers.

In the beginning the work required a leap of faith from both ward staff and service-user link workers. The link workers needed to have faith that the ward staff would welcome them, be open to ideas, and make real changes. The staff needed to have faith that the link workers would lead the meetings professionally and present the feedback in such a way that the staff would not feel they were being personally criticised for any problems with the service.

The project has led to small and large changes. Some service users were anxious at meal times as the queue for the meal trolley blocked the door and made them feel hemmed in. Nobody had told the staff, but they felt able to tell the link workers who passed on this information and the trolley was moved.

The link workers discovered that service users are often curious about sections of the Mental Health Act that are not directly relevant to them. There is now brief information on the Mental Health Act available on the ward for anyone who is interested.

Something slightly more difficult to tackle was the fact that inpatient service users have a lot of time on their hands with nothing to do. The few group activities done on the ward were very much appreciated, but there were not enough of them. The information and impetus gained from the meetings between the link workers and service users led first to changes on their ward and informed improvements across the unit. There are now three activities workers and a programme of activities for the unit which includes groups organised by ward staff, community and occupational therapy staff and social events run by volunteers.

Even huge ideas for environmental improvements have led to changes. It was due to service users' suggestions for a café that connections were made with the Women's Royal Voluntary Service and a grant was arranged from the King's Fund. There is now a café in the reception area, with décor designed jointly by staff and service users.

The latest project in 2004 is an information trolley jointly run by staff and service-users. This will be supported by clinical staff and a patient information and support officer who is being employed in response to service users' concerns.



Neurosciences Centre

Patients' panel

Hammersmith Hospitals NHS Trust

What is the panel?

In January 2003, the West London Neurosciences Centre hosted the first patients' panel with the aim of making sure service users help shape and plan neurological services for the future.

A range of individuals and organisations took part. These included:

- patients and carers who use or have used the service;
- members of local patient support groups such as the MS Society and Motor Neurone Disease Society;
- representatives of other local voluntary organisations such as Hammersmith and Fulham Action For Disability (HAFAD);
- health professionals, including the Director of Clinical Services, consultants, the neurosciences specialist social worker, specialist nurses and other health professionals;
- other trust staff;
- representatives from the local primary care trust, including relevant community-based health professionals; and
- representatives from the local authority.

The event took place in the evening at Charing Cross Hospital and a light supper was provided for those taking part.

What did patients say?

Patients and carers highlighted several issues. One of the main themes was the need for more active support and follow-up in the community.

The outcome

As a direct result of feedback from patients who took part in the panel, the acute trust, social services and the MS Society worked to set up the Multiple Sclerosis (MS) Multidisciplinary Clinic for the Hammersmith and Fulham community. The clinic was opened in September 2003 at the Sunberry Day Centre in Fulham.



Benefits for the patients

These include:

- access to specialist medical, nursing, therapy and social support;
- a greater choice for patients by increasing their knowledge of what is available;
- patients being actively involved in the decision-making process; and
- a psychological boost for a group of people who had felt invisible and excluded.

There has not been a formal audit or assessment. However feedback suggests that patients are very positive about the clinic.

What next?

To:

- assess the first six months' running of the clinic;
- encourage GPs to use the clinic and the team;
- continue to be a source of support and care for each person with MS;
- identify and respond to the needs of people with MS;
- serve as an example which other specialist areas can follow;
- be a learning resource for acute, primary and voluntary services; and
- hold regular neurosciences panels.



Older people

Patients' stories

Cherrydown Ward, Basildon Mental Health Unit, South Essex Partnership NHS Trust

Cherrydown Ward in Basildon Mental Health Unit is part of South Essex Partnership NHS Trust. This is a mental health and learning disability trust that provides care for elderly patients who are mentally ill with conditions such as Alzheimer's.

The ward support workers sit down with the patients and collect stories of important life events, family photographs and so on. Our staff and carers have reported that as a result of this, patients become people again.

The outcome

Collecting patients' stories has led to new ways of working. The manager of the unit said:

"The first patients' stories we did identified some unmet spiritual needs, so between carers, staff and service users we arranged for a Roman Catholic priest to visit us and he now comes in once a week for services and to talk to patients. We have also set up a monthly forum for all faiths, which we also use as staff training to raise their awareness of the issues and to help to ascertain the needs of other faiths."

The whole experience has had a huge effect on staff morale. All staff are involved in the project. Collecting the stories is a very intimate and personal process that has had some startling effects. The manager said that one member of staff, who has now started her nurse training, said she felt like she'd "won the lottery" when she made a connection with a badly depressed patient through a Rod Stewart song uncovered in her patient's story.

Patients' stories are now included in the care planning process from the start.

Orthopaedic, Gynaecology and Urology

Nottingham City Hospital

Nottingham City Hospital is an acute teaching hospital with 1100 beds, 6000 staff and around 290,000 inpatients and outpatients a year. As part of our work to improve services we have worked with local patient organisations and involved over 750 patients through interviews, focus groups, questionnaires and patients' stories. We have also:

- shadowed 1000 patients through their 'journey' within the hospital;
- had patients on working groups; and
- held process-mapping days.

We have a strong culture of involving patients in the 'big' things. However, the following examples are more about the smaller issues that help to make the patients' experience a more positive one.

The example from the Orthopaedic, Gynaecology and Urology Directorates was part of a pilot that we have now extended across the hospital. Responses are recorded through the PALS database so that we can pick up any trends and examples of good practice.

Patients said



"Nowhere to have a bit of quiet space."

Patient stories



"After a big operation all the patient wants to do is settle down and sleep."

Patient Involvement Action Group
(Orthopaedics, Gynaecology
and Urology)



"Visiting should be restricted till after lunch to allow patients privacy when getting up."

Patients were commenting on the lack of peace and quiet on the ward, either because of routine activities or the constant stream of visitors. These issues were also raised by individual patients through the Patient Involvement Action Group and again in more detail during patient story interviews. We feel that rest and relaxation are vital for our patients' psychological wellbeing and their physical recovery after an operation. But we also recognise the need for flexible visiting arrangements to meet individual patient needs.

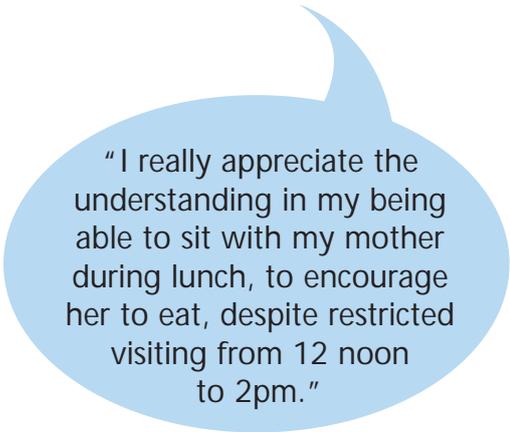


What we did

We:

- set up a quiet time in each ward area. These times usually follow set mealtimes;
- made sure routine ward activity is kept to a minimum;
- made sure that curtains are drawn and lights dimmed;
- encouraged patients to rest on their beds and relax;
- asked visitors to respect these times;
- made sure other professionals are flexible in their working during these periods;
- worked with other departments such as x-ray;
- made sure that day rooms are still available for patients who do not want to have this quiet period.

Visitors said



"I really appreciate the understanding in my being able to sit with my mother during lunch, to encourage her to eat, despite restricted visiting from 12 noon to 2pm."



"I think this period includes rest for patients and for visitors too."

We will:

- continue to monitor the comments we receive from the Patient Involvement Action Group as to how satisfied patients are with the quiet period;
- ask patients for their opinions during future patient stories; and
- monitor comments from patients and staff on privacy, dignity and self-care standards.



“ Our services can be better than this”

Looking for ways to improve outpatient services

Morecambe Bay NHS Hospitals Trust

A modern matron writes...

How it was

Creating the trust involved bringing together services at several local hospitals where outpatient services were provided. The main sites were at Royal Lancaster Infirmary, Westmorland General Hospital in Kendal, and Furness General Hospital in Barrow. However after the initial reorganisation, little had been done to introduce common ways of working across outpatient services.

- The results of a national outpatient survey in 2003 noted that ‘communications’ tended to be a problem in many departments. The services we ran were no exception, although locally the service received few negative comments from patients.
- In 2003 the trust appointed a modern matron for outpatient services. This raised questions about ways to improve standards across the different outpatient areas managed by the trust.
- We decided to join the Clinical Governance Development Programme. This seemed to offer the type of support needed to help staff explore ways of improving their services and working together within common systems.
- We invited a team of six people from a range of disciplines to take the work forward in late 2003. Within the trust we identified two senior members of staff who would help with and support the team discussions.

How the team did it

- A local project offered the team an early insight into patients’ views of how outpatient services worked. The local training department had set up ‘Management in Action’ (MiA), a scheme to support senior staff development. MiA was involved in interviewing patients and asking them to describe their experiences at the hospital.
- The videos of the interviews helped the team realise that it was not seeing the issues in outpatient services that were important to patients.

To take their work forward the team decided to use a technique (a ‘five senses’ study) that had been developed with the local Cancer Collaborative. This study took place in our three main outpatient areas. It focused on a patient volunteer at each site who spent about two hours observing each outpatient area.

- The ‘five senses’ study involved observing services and recording issues about what patients could:

- 
- see, hear, smell, touch (taken to mean the feel of the service – how hectic it was and so on); and
 - the taste (taken to relate to how clean the units were.)
 - The results of the study were fed back straight away to members of the team.

These results helped the team to develop a plan for immediate action. Some of the changes that followed the study were:

- introducing background music to improve the general mood in the areas and help patients relax. (patients had criticised – ‘too quiet’ or ‘too noisy’);
- putting up extra whiteboards for staff to report delays in the running of clinics and so on; and
- making new arrangements for delivering supplies. (In the past they were often left where patients could fall over them.)

How it's improved

- The team is encouraged by the early effect of its efforts. It is starting to see improvements across the whole outpatient service.
- Since the work started, an outpatient survey has been carried out to help the trust compare current performance against the situation reported earlier. The results are encouraging. Patients said:

“I feel that medical and nursing staff do a fantastic job – how they cope with all the pressure I do not know.”

“What is the collective noun for a group of Florence Nightingales?”

- The survey continues to highlight other areas of the service where things could be better. These include:
 - shorter waiting times;
 - better information about appointments;
 - more comfortable seating; and
 - water fountains and drinks machines.
- Examples of the further actions included – providing better information (a list of ‘top tips’) with initial appointment letters to make sure that patients are properly prepared for their consultation. Another issue is the old-fashioned way that appointment letters and the material sent out with them are still folded manually and put into envelopes. We are taking steps to introduce machines for this process.
- The team is determined to build on its early success and carry on with its continuous improvement process.



Paediatric physiotherapy group

Dartford, Gravesham and Swanley Primary Care Trust

Background

Because of a staffing crisis in the Paediatric Physiotherapy Department, services for 240 children aged 0 to 18 receiving physiotherapy were at risk.

How could we deliver our services differently but effectively with limited staffing levels, and how could we also support families with long-term needs? Our biggest concern was the under-five group. Some of these children were used to having regular one-to-one physiotherapy sessions with the therapist providing all the treatment.

What did we do?

We involved parents in a discussion and consultation period. We explained to them the staff shortages and the need to re-design the service. As a team we identified the children according to their gross motor abilities and their need for regular physiotherapy sessions. We discussed setting up three groups for children under five, and considered:

- the aims of these groups;
- the admission conditions for each group;
- the structure of the groups; and
- record keeping.

We then set up the following three groups.

- 1 **The teddy bear group** was set up for children to develop head and trunk control.
- 2 **The rabbit group** was set up to develop sitting balance and crawling.
- 3 **The kangaroo group** was set up to develop standing balance, walking and mobility.

We decided that:

- a physiotherapist would lead the groups and would have a physiotherapy assistant to help;
- parents would work with their child during group sessions so that they could develop their skills and use them at home;
- sessions would take place every two weeks; and
- therapy would include play and singing.



We realised that we would need an extra pair of hands to help set up these sessions and also during the sessions. We asked our volunteer co-ordinator for help and she received an overwhelming response to an advert in the local paper. Following a selection and vetting process, we were able to recruit 10 volunteers.

The group sessions last for up to 45 minutes and are followed by a refreshment break for parents. Sometimes speakers from other organisations come and talk to parents. After the refreshment break the teddy bear and rabbit groups have hydrotherapy sessions.

After a three-month trial period we asked the parents to fill in a questionnaire and give us their views on how the groups were working. We also asked them for ideas on how we could improve the service further.

As a result of this we redesigned the kangaroo group to bring together children of similar learning abilities.

Now that parents are involved the groups are developing all the time with new ideas. These include the teddy bear group meeting in the summer holidays and on Saturday mornings so that dads can be more involved.

Outcomes and benefits

- We now work with up to eight children in one session, compared with just one child earlier.
- We have a healthy partnership with the voluntary sector. All our volunteers have learnt a lot on the job and provide vital support to the parents and staff.
- Parents have developed excellent handling skills and are using these skills at home. They are more motivated to take responsibility for treating and stimulating their child.
- The parents have developed their own support relationships, and some have also organised outings.
- There is a closer working relationship between parents and staff.

Recently the group organised a 'pampering day' for the mothers. They did this with the help of a local college where the students learn massage and reflexology.



People with long-term conditions Involving PALS

Taunton Deane Primary Care Trust

We asked the PCT's PALS to listen to the concerns raised by the Parkinson's Association and individual carers. The concerns were that:

- patients adjust the timing of their medication to make the most of the benefit it provides;
- GPs rarely know when patients actually take their medication, but on admission to hospital, tablets are routinely removed from all patients and are given out on drug rounds in line with admission notes from the GP;
- any change in timing can affect patients' ability to swallow; and
- carers usually know the best time for a patient to take their medication, but often nobody asks them.

The PCT's PALS worked with the medical team and a specialist nurse at Taunton and Somerset NHS Trust. As a result of this:

- the hospital tests the swallowing reflexes of patients with Parkinson's when they are admitted to hospital; and
- patients being in control of their own medication is being tried out at the hospital.

We have reported these changes back to the Parkinson's Association.

Taunton Deane PCT PALS then worked with the Carers' Support Team and the acute trust's PALS. As a result of this:

- we held an 'Engaging with Carers' event at the hospital; and
- the Carers Support Team has appointed an extra senior carers' support worker to raise awareness on the wards of the importance of involving carers.



Phlebotomy services

Press release

Cheltenham and Tewkesbury Primary Care Trust

You said... **“We have to wait a long time for a blood test”** ... so we did something about it!

Blood tests at Tewkesbury Hospital

Over the past few months, there have been growing problems with patients being able to get in to see the phlebotomist for a blood test at Tewkesbury Hospital. Patients were having to wait a long time once they arrived to have their blood taken, or in some cases weren't able to have it taken at all. Individual patients and the local Patient Forum contacted Cheltenham and Tewkesbury Primary Care Trust (PCT) to see what could be done to improve the service.

What changes are taking place?

- In partnership with Tewkesbury Hospital staff and GPs we are introducing an appointment system for all patients who go to Tewkesbury Hospital to have a blood test.
- The appointment system will start from Tuesday 1 June for a trial period to see whether this improves patients' access to the service.
- Patients **must** now make appointments for blood tests by phoning the receptionist at their GP practice.
- We have given each of the three Tewkesbury GP practices a fixed number of appointments for their patients each day. (The number of appointments is based on the number of patients registered with each practice.)
- Patients who turn up without an appointment, as they would under the old system, will not be seen.

What patients have said about the changes

“The new appointment system for having blood taken is very good and saves long waiting times.”

“The excellent blood-sampling service at Tewkesbury Hospital has been transformed by the appointments system which is now being operated successfully via GP's surgeries. As a “before and after” patient I can vouch for this. Patients have benefited by not having long waits. The staff now appear to be less stressed and the reception area is no longer overcrowded at the start of the day. Altogether a successful innovation.”

“The new blood-taking system works very well, much easier and there is now no waiting.”



Primary care

Proposed closure of a branch surgery in Eccles

PALS support in the community

Maidstone Weald Primary Care Trust

When two doctors who ran a practice in the area of Medway PCT, and a branch surgery in Eccles (a small village in the Maidstone Weald PCT area), announced that they were retiring, we proposed to close Eccles surgery. This branch surgery served relatively few patients, and other practices nearby were prepared and able to take on those patients.

The residents of Eccles were shocked by this announcement, and over 60 people contacted the Patient Advice and Liaison Service (PALS) about it. Some people wanted information about how to change to another doctor. But many were concerned about losing the surgery and on-site pharmacy service in their village.

PALS passed this information on to our Director of Commissioning and Partnership Development Manager, who accepted an invitation to attend a meeting set up by Eccles Parish Council to listen to what the community had to say.

After hearing residents' views at the meeting, we set up a working group to decide the best way forward for the Eccles surgery. The group included:

- a parish council representative;
- a representative from the residents' association;
- a County Councillor;
- staff from pharmacy and primary care development;
- communications staff; and
- PALS staff and health visitors.

It was agreed that this group would decide the future of GP services for the residents of Eccles.

The group met regularly to discuss issues such as:

- the availability of GPs who may be interested in taking on the Eccles surgery as a branch;
- which services should be available;
- how to maintain the clinics and pharmacy; and
- how to manage the service while longer-term decisions were made about leases and staffing.



We negotiated and paid a lease for the building and put in a locum doctor to provide a service while these discussions took place. Our pharmacy advisors also worked with a local pharmacy to make sure prescription medication was delivered to people in the village who could not get to a pharmacy.

Our PALS officer went to the Eccles surgery for two four-hour PALS surgery sessions to:

- talk to residents and explain what was happening;
- reassure them that they did not need to worry about the short-term provision of services;
- explain how to get access to pharmacy services; and
- continue to take comments and ideas to feed into the working group.

The outcome

The working group concluded that the community in Eccles was likely to expand and that there was a real demand for the surgery to continue. Again we asked neighbouring practices to consider providing a service from the premises. When more than one doctor expressed an interest, we set up an interviewing panel which included a representative of patients from the village.

Long-term learning

- We need to be aware of the potential issues when a branch surgery in our area is part of a practice supported by a neighbouring PCT. We have set up a better communication procedure to help us in these cases.
- When considering changes to GP service provision, we need to listen to the views of communities in a structured way. We can then find out which issues will affect them. For example, moving a pharmacy service, even if it is only moved a short distance away. This is now part of our primary care development practice.

Final comment

At the time of writing, the process is not yet complete, but Maidstone Weald Primary Care Trust is planning to provide GP services to Eccles branch surgery for the foreseeable future, and people in the village are very happy with this.



Sexual health clinic

Patients' network

Camden Primary Care Trust

Aims

The aim of Bloomsbury Clinic Patients' Network was to provide leadership to make the existing patient advisor system a more inclusive and representative group for HIV-positive patients. These patients would hopefully be able to make healthier lifestyle and treatment choices.

Goals

The goals were to:

- increase patient involvement and responsibility;
- improve links between existing clinic services and those outside;
- encourage support for each other; and
- develop an approach which covers every aspect of living with HIV.

We aimed to make sure that all HIV-positive patients were informed, consulted and allowed to have their say in the clinic in all areas relating to their physical and emotional wellbeing. We also aimed to help and encourage them to take charge of their health. We wanted the network to encourage expert patients to provide support for those who were newly diagnosed with HIV, and for it to improve sexual health.

We planned to achieve these aims through the network by organising regular meetings, workshops and other events. These would encourage communication between patients and health care providers. Through a series of workshops, we also hoped to tackle some of the most important challenges facing people in managing this disease.

Actual achievements

The network succeeded in reaching out to under-represented minority groups – in particular, heterosexual female African patients, and heterosexual couples. It moved from being an advisory group to becoming a fully independent patient network, responsible for its own membership, recruitment and organisation. It also became more involved in the clinic's decision-making process by sending representatives to monthly senior-management meetings.

Most importantly, the network made a major contribution to setting up a new in-house pharmacy and recruiting a part-time professional patient representative.



Other outcomes

Other changes have resulted from this work. These include:

- better toilet facilities;
- a system of early-morning blood tests for patients who are working;
- user representatives attending and being consulted at senior-management meetings;
- an 'at home' clinic for patients to receive blood test results and order repeat prescriptions by phone;
- patient information notice boards at the clinic; and
- regular meetings for patients arranged by patients. These take place at the clinic and are attended by health care providers.

Overall effect

This work has:

- reduced the sense of isolation which some patients experience;
- given them a greater understanding of the challenges which others living with HIV face;
- provided an opportunity for HIV-positive men and women of different sexualities and cultural backgrounds to meet and share their experiences;
- made the clinic a more friendly and accessible place; and
- opened up a great deal of discussion between patients and NHS management. This in turn has improved services and the health of patients.



Strokewatch

A local stroke survivor group

Hull and East Riding Stroke Service

An organised pathway of care for stroke patients and their families was set up across the acute and community services in Hull and East Riding of Yorkshire.

A local stroke survivor group known locally and nationally as Strokewatch, lobbied various organisations for resources for stroke services. Staff across the service worked very closely with Strokewatch. Patient and carer representatives have been involved, and have open invitations to all stroke meetings across the acute and community service. These representatives continuously influenced the way stroke services were developed.

Working together in this way has resulted in many achievements. The staff feel well supported by the representatives from the local stroke survivor group, who are watching and influencing the service grow and develop and have an open and honest working relationship with the group.

Part of the clinical governance framework involves a user and carer subgroup. This group focuses on service development from the patients' and carers' points of view.

Outcomes

- **Information for patients and personal health records**

These are now given to all stroke patients and their families as they come through the acute stroke unit at the Hull Royal Infirmary. It includes information about:

- their type of stroke, personal risk factors and rehabilitation plans;
- prescribed medications and personal rehabilitation goals for patients to continue when they go home; and
- the local support network services.

- **Six evaluation workshops across Hull and East Riding in 2003**

The trust invited patients with experience of the service, and carers, to talk about their experiences and any ideas they have to improve it. The trust produced a report which identified the main themes from the workshops. The points raised were fed into the trust's business planning process and training, education and ongoing service developments.

- **Support to a local training and education programme for professionals working in the stroke service**

Members attend to share their experiences as stroke survivors or carers with professionals. They tell the professionals about the things that they would like professionals to do or not do.



- **An ongoing system for feedback from patients and carers**

Feedback forms are distributed across all parts of the service in the acute hospital and community rehabilitation units. Patients and carers are invited to offer both positive and negative comments at any time. These comments are passed to the nurse consultant, who then takes suitable action. This allows us to support people before things become difficult. It also provides a continuing source of feedback to improve staff morale.

- **Working closely with the Stroke Association to further develop the role of family support organisers**

The PCTs contract this service from the Stroke Association. Staff follow up and support patients and their families during the early months after a stroke. The changes we are making aim to:

- involve the family support team more closely in the service; and
- improve acute and community co-ordination and support for stroke patients and their families.

Sure Start Spa Spiders Family Planning Service

Doncaster West Primary Care Trust

Sure Start Spa Spiders is a PCT led Sure Start Programme. One of the five objectives it works towards is improving the health of families with children under the age of four. During early consultations with local families, a mother of two wrote the following comment in her account of what it was like to be a parent in Astern.

“I hate making appointments with my local GP. I’ve even been told off over the phone for leaving it a bit late. It was 9.30 in the morning and my child had been awake most of the night. When I do get an appointment I can sometimes be waiting an hour or more to see the doctor. There is little to occupy my children except for a little table with beads on squeezed in the far corner between two chairs. A small child has barely enough room to get round it. I neglect my own health because of this. I rarely see a doctor because there is no-one to look after my children.”

As a result of this and other comments we received from parents, we set up a task group of parents and local health professionals to look at how we could improve services to overcome the problems.

The main area of concern among the parents was the difficulty of getting to local family-planning services. The concerns centered around:

- unsuitable times of opening – one session a week, at teatime;
- the location of the service – at the local health centre at the same time as the main surgery which mothers felt affected confidentiality;
- all GPs being male;
- parents with no family support having to take their children with them - children being present when personal discussions or examinations were taking place; and
- not having enough time to discuss concerns in depth.

In response to these concerns, Sure Start offered to fund two open drop-in family-planning sessions a week. These sessions each lasted two-and-a-half-hours. They were led by the Sure Start school nurse and midwife, (both trained in family planning), and were supported by a female GP from our sexual health service. Sure Start also offered to fund a crèche at these sessions so that parents could discuss their concerns in a relaxed, non-rushed setting, knowing their children were in safe hands. The sessions ran in a local youth club away from the main surgery, and tea and coffee were available to add to parents’ comfort.

The clinic has been running since September 2003. It is well attended and highly valued by parents. One unexpected result has been that teenage women who have never taken any



sexual health advice now feel comfortable enough to do so in what, for them, is a more familiar and acceptable setting.

There is evidence to show that, as a result of this new service:

- younger women are asking for contraceptive advice earlier than before;
- more sexually transmitted diseases are being detected and treated early;
- teenage pregnancies are being diagnosed earlier, giving more time for parents to make informed decisions on how to manage the pregnancy; and
- parents are more comfortable attending because of the all-female staff.

As a result of the increased contact with teenagers, we have also set up an extra teenage antenatal clinic at the Sure Start premises. This is proving popular with teenage parents.

'The little things are important'

Exit cards

Taunton and Somerset NHS Trust

Taunton and Somerset NHS Trust is based at Musgrove Park Hospital in Taunton.

Why exit cards?

- The NHS Complaints Reform (2003) sets out a vision for a service designed around the patient which responds to patients' needs. It states that:
'All patients leaving hospital will be given the opportunity to record their views about standards of care they have received.'
- Our PPI Strategy identified exit cards as a way of gathering information about patients' experiences.
- The good hospital guide (which is an annual survey of all the acute hospitals in the country) was published in May. One of the measures used for this guide is patient satisfaction. Under this section we were rated best in the West and second in the country.

What we did

- We chose to use a simple card format which asks two questions. This gives patients the opportunity to tell us what their concerns are.
- We made the cards available across the hospital for patients to fill in before they are discharged (if they want to). Patients then post the cards in a secure box which matrons regularly empty. Matrons then record patients' replies.
- We asked children on the paediatric wards to design their own exit card.

How we did it

We:

- consulted users and staff;
- carried out a trial scheme;
- gave each patient an exit card before they were discharged;
- collected the results and presented them to other staff. We also displayed them on the PALS boards for patients and staff; and
- changed our practices as a result of patients' comments.



Positive results

- Over three-quarters of patients said that the one thing that was best about their stay was the staff.
- The cards have highlighted that it is often the little things which are most important.

What have we changed? – Just a few examples

We:

- offer patients an extra drink before bedtime because many of them said the availability of drinks later in the evening was poor. We also changed the opening hours of the coffee shop to meet patients' and visitors' needs;
- reintroduced a 'newspaper round' (this had not operated for sometime);
- oiled squeaking trolley wheels so they did not disturb patients!
- introduced a whole range of changes in all areas to reduce noise at night;
- have reviewed the letters patients receive from us before they are admitted. We changed their content and style to make them more patient-and user-friendly and more consistent.

Conclusions

- Exit cards give patients the opportunity to give us both positive and negative comments and suggestions.
- The positive comments have had a good effect on staff morale.
- Because the card is so simple and easy to use the response rate is good. Negative comments are constructive and have mainly highlighted things we can change. To most patients it's the little things that make the difference.

'Time to talk!'

East Somerset NHS Trust

At our annual Patient and Public Involvement Conference an ex-patient told us, "Nurses don't talk to patients."... so we asked him to help us do something about it!

We set up a project group that included:

- members of staff
- representatives from our user group; and
- the ex-patient who had told us his concerns.

The group's task was to:

- review how nurses gained information about patients' needs and concerns; and
- introduce a new system where good records would provide evidence of any concerns raised and actions taken.

We introduced a daily assessment for nurses to carry out. This encouraged patients to express their needs and concerns. We highlighted four main categories as a basis for assessing emotional wellbeing. The patients themselves had identified these categories.

- How do I feel?
- What is happening to me here in hospital?
- What is likely to happen to me in the future?
- What problems might I or my family have when I leave hospital?

Keeping good records to provide accurate evidence of what was happening on the two wards chosen for the test project was an essential part of the project.

Results have been excellent.

Changes taking place as a result of the project

- All patients on the test wards have the opportunity to talk with a nurse to identify their emotional needs, as they see them.
- We are standardising the evaluation sheets used on the two test wards so that they can be used throughout the trust.
- The project is being jointly presented by a user and a member of staff at a trust-wide clinical governance meeting. In this way we hope to share our learning and improve our trust-wide approach to meeting patients' emotional needs.
- We will extend the project across all wards over the next few months.

Welcome evenings

Sussex Cancer Centre

Over the last year, the Sussex Cancer Centre has been opening up its doors to patients who are about to have radiotherapy. The aim is to help ease some of the fear of radiotherapy treatment.

Two years ago we carried out a mapping exercise of radiotherapy services which involved both staff and patients. This exercise highlighted that patients were unaware of the 'behind the scenes' activity in the radiotherapy unit. As a result we concluded that if patients received better information, it would improve their experience of waiting for radiotherapy treatment and of the treatment itself.

We set up 'welcome evening' events for new patients and their guests.

- At first we are focusing on breast and prostate patients as they had the longest waits for treatment.
- Sixteen patients and their guests attend each month and more sessions are being planned.
- Six staff from our centre explain what will happen before and during treatment. They also give a guided tour of the department and a demonstration of the treatment machines. They then give patients the opportunity to express their concerns and ask questions.

User involvement in the welcome evenings

Members of the Seaford Cancer Support Group, who were involved in the mapping exercise, are available to answer questions from the patient's point of view. The group provides refreshments during the evening and creates an atmosphere where patients and their guests can ask questions.

An ex-patient said:

"We get a kick out of doing it and have no problem in getting volunteers to help. I remember the trauma and worry I felt when I had radiotherapy five years ago. I live a little way from the cancer centre, so even finding the front door was a worry. I imagined all sorts of scary things. Now we can talk about those worries early on and save weeks of sleepless nights. The welcome evenings give people the opportunity to meet people in the same boat."

Feedback

Feedback from patients and guests has been consistently good. Patients say they feel more confident about their treatment. One patient said,

"I can't say I'm looking forward to the treatment, but I know now that I can cope OK."



A thank you letter sent to the department said:

“My wife and I would like to express our appreciation to you and all your colleagues. We left with the utmost confidence in a dedicated, professional team and the availability of the latest technology.”

Outcomes

- Patients seem more relaxed when they attend the department.
- There has been a reduction in the number of phone calls made to superintendent radiographers by patients waiting for treatment.
- Staff need to spend less time explaining what is going to happen.

The future

- The evenings have been so successful that we are planning to increase the numbers attending to thirty patients and thirty guests.
- We will also be arranging a ‘welcome evening’ for the nursing staff from outpatients. These nurses are often present when patients receive news about their treatment. It means that they will be able to answer many more questions as a result of the evening.



Working with travellers in St Day

West of Cornwall Primary Care Trust

Feedback from travellers has had a real effect in the west of Cornwall area. A local health visitor has worked alongside colleagues in education and social services to find out what we can do to improve life for travellers.

Women on the site in St Day made it clear they wanted a women's group. This would provide:

- a social evening;
- a place to go to sew and cook; and
- an evening free from childcare.

The health visitor secured £150 to start the group, which met for six weeks, over Christmas 2003.

We also set up a traveller's forum. This involved:

- a traveller;
- the health visitor;
- the travellers' education liaison officer; and
- social services.

The traveller captured the views from the travellers and fed them back to the forum.

The forum put forward a £200,000 bid to the Learning Skills Council to fund two development workers. The bid was successful, and the development workers will support the travellers' education, health and social needs – including the women's group.

The importance of using appropriate language

Examples of unintentional gaffes

These examples are real. They were put forward in response to the Choice, Responsiveness and Equity consultation. They show how NHS organisations sometimes use language that gives inappropriate messages.

'What Choices Do Patients/Users/Carers Want?

There is a general view that patients will want to have choices, but that they will want to make these choices with informed health and social care support. Some patients may feel able to access information, which allows them to make their own choices. However, the majority of patients will want some kind of support often in the form of someone that they know and respect either within a primary care, community or social care setting. It is felt that in general patients want good quality *local* health and social care.'

The message here is that it is the organisation's view of what patients want, rather than a statement setting out what patients have said they want.

If patients and the public have been involved, an organisation can say, 'Some patients feel able to access information, and most patients want some kind of support', as it has the evidence to support these statements.

'We focused on what we felt were the key points: communication, information and feedback.'

The message this sentence gives is that the organisation has decided which points to focus on, rather than the decision being based on what patients and the public have said.

1. What choices do patients/users/carers want?

We feel that the nature of the PCT population lends itself more to making informed choices **during** their pathway of care, rather than about where the care itself should be delivered.

'We feel' suggests that it is the PCT's view about the population's ability to make informed choices during their care, rather than about where the care itself should be delivered. This may not be the view of local people.

Statements about populations, patients and the public must reflect the views of those people and not the assumptions of the NHS.



References

Building on the Best, December 2003

Choice, Responsiveness and Equity. A national consultation, Department of Health, Autumn 2003

Involvement to Improvement, i2i, Commission for Health Improvement, February 2004

NHS Plan, July 2000

Patient and Public Involvement in Health: The Evidence for Policy Implementation, Department of Health, May 2004

Strengthening Accountability, Policy and practical guidance for section 11 of the Health and Social Care Act, 2001, Department of Health, February 2003

Technical Note for the Spending Review 2004

Public Service Agreement 2005-2008, Department of Health, 2004

The NHS Improvement Plan, HM Government and Department of Health, June 2004



Acknowledgements

We would like to thank the following people and organisations for their contributions to this document.

The national Strategic Health Authorities PPI leads network for their help in collecting the examples.

The organisations that put forward examples we have not included in this document. (We did not have room to print all of them.)

The organisations that put forward the examples that illustrate this document.

The PPI editorial team at the Department of Health.

Harry Cayton, Director for Patients and the Public, Department of Health.

Particular thanks to Jenny de Ville, Head of Patient and Public Involvement at South East London Strategic Health Authority, for her work in producing this document.

© Crown copyright 2004

40552 1p 10k Oct 04 (BEL)

If you require further copies of this title quote
40552/Getting over the wall and contact:

DH Publications Orderline
PO Box 777
London SE1 6XH
Tel: 08701 555 455
Fax: 01623 724 524
E-mail: dh@prolog.uk.com

08700 102 870 – Textphone (for minicom users)
for the hard of hearing 8am to 6pm
Monday to Friday.

40552/Getting over the wall can also be made available on request in Braille,
on audio-cassette tape, on disk and in large print.

www.dh.gov.uk/Publications

