

Improvement Leaders' Guide
Involving patients and carers
General improvement skills



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Improvement Leaders' Guides

How you use the Improvement Leaders' Guides is not prescriptive. You can start wherever is best for you, however experience has shown us that some of the Improvement Leaders' Guides are best used sequentially.

The ideas and advice in these Improvement Leaders' Guides will provide a foundation for all your improvement work:

- Improvement knowledge and skills
- Managing the human dimensions of change
- Building and nurturing an improvement culture
- Working with groups
- Evaluating improvement
- Leading improvement

These Improvement Leaders' Guides will give you the basic tools and techniques:

- ▶ Involving patients and carers
- Process mapping, analysis and redesign
- Measurement for improvement
- Matching capacity and demand

These Improvement Leaders' Guides build on the basic tools and techniques:

- Working in systems
- Redesigning roles
- Improving flow

You will find all these Improvement Leaders' Guides at www.modern.nhs.uk/improvementguides

Every single person is enabled, encouraged and capable to work with others to improve their part of the service

Discipline of Improvement in Health and Social Care

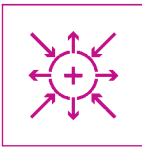


I am going in completely blind - I have no idea what is expected of me, if anything for that matter. Am I just a token gesture or am I there as somebody who has some impact?

Patient

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1. Introduction to patient involvement

A note about terminology

There are a number of different terms in general use to describe people who use health and social care services. For the purposes of consistency, and to reduce confusion, this guide uses the term 'patient' throughout to cover patients, users, carers, clients and the public. The spirit of this guide is to strengthen collaboration and partnership between all the many different people involved in care, whether they are receivers or providers, however they may be labelled.

About this Improvement Leaders' Guide

This guide is primarily written for those of you with responsibility for improvement, who have a particular desire to involve patients and carers in the process but who may have little previous experience of doing so. It aims to:

- offer a framework for patient involvement in the improvement of care
- describe and illustrate practical methods that are manageable in everyday practice and that have led to demonstrable improvements in patients' experience
- outline organisational implications that need to be considered

The experience of those already engaged in involving patients has been distilled to offer some current thinking about how to make it an ongoing process. A selection of stories is included, which describe a wide range of practical experiences and offer clues to those wanting to do something similar. In some ways the stories may be seen as a celebration of current activity. It is only possible to reflect a small proportion of the work that is going on across the health and social care, and the stories reflect different stages of developing the type of partnerships that this guide advocates. One thing they all have in common, however, is a genuine commitment to move towards the radically different ways of shared working, upon which sustainable and effective improvement depends.

Touchstones for involvement as a continuous and effective process:

- involve patients from the very beginning and at all stages
- before you start, gain the enthusiasm and commitment of all those who will have to improve the way they do things
- make sure that people in the organisation, including key decision makers, know about your plans and will support any findings to improve practice
- make sure you learn as you go, so that you can do it better next time
- provide appropriate resources and support to all involved

1.1 The bigger picture of patient involvement

Patient and public involvement is a large and complex subject. Before breaking it down into more manageable chunks, a look at the big picture can help us to understand where we are focusing our improvement and who we should be involving.

The table below shows one possible model. Broadly speaking, it suggests that involvement may occur at a number of different levels of contact, ranging from patients' treatment to strategic policy making, with essentially three broad modes of participation: informing, consulting and partnership.

An increasing number of initiatives in health and social care explore how to actively engage members of the public in determining local priorities. Such approaches demand active involvement of local community members in dialogue about local provision and are not included in this guide. Our focus is more around the shaded elements in the table below: on service delivery and treatment, with the emphasis on active partnership leading to jointly designed and implemented improvements in these two areas.

Different elements of patient involvement			
	Strategic Policy Making	Service Development	Treatment Process
Informing			
Consulting			
Partnership			

1.2 Background and context

There is a strong and widely held view that involving patients in decisions about healthcare at both personal and strategic levels is fundamentally important to the improvement of health and social care services, as well as being a basic right.

One key report which has had a great impact on the delivery of healthcare, the Kennedy Report on the Bristol Royal Infirmary Inquiry published in July 2001, recommended that “the perspectives of patients and of the public must be heard and taken into account”.

It is now a statutory duty for NHS Trusts, Primary Care Trusts and Strategic Health Authorities to involve and consult patients and the public in the development of proposals for change. For more information about patient and public involvement initiatives go to the publication section at www.dh.gov.uk/policyandguidance/organisationpolicy/patientandpublicinvolvement

Potential benefits for patients and carers may include:

- better quality services that are more responsive to the needs of patients, leading to better outcomes of care and improvements in health and well-being
- policy and planning decisions that are more patient focused
- improved communications between organisations and the communities they serve
- greater ownership of local health services, and a stronger understanding of why and how they need to change and develop

Expert Advisor Model versus Partnership Model	
Expert Advisor	Partnership
<ul style="list-style-type: none"> • define patient needs • give advice • solve problems • decide what information they need • encourage dependency 	<ul style="list-style-type: none"> • elicit patient needs • discuss options • explore solutions • ask what information they want • empower and enable

It is important to emphasise that greater involvement of patients, carers and the public in planning and delivering health and social care will result in mutual benefit to patients, carers and providers alike.

The emphasis is very much on creating genuine, ongoing partnerships where all the people involved are acknowledged as having a particular and unique contribution and are respected as equals. We need to embrace methods that will advance this. There is a growing shift beyond traditional approaches, where involvement often meant consultation that stopped once patients' views had been obtained. In the 21st century involvement in health and social care means the development of long-term collaborative partnerships between planners, service providers, patients and carers. This is sometimes described as moving from expert advisor to partnership and some of the necessary shifts are summarised in the table opposite.

Staff involvement must be considered as equally important, otherwise there is a danger that the pendulum may swing to the other extreme, with health and social care staff feeling that they are not being listened to. Working in this way will take time to develop, not least because both patients and staff can feel anxious and threatened about getting involved in something new. Some of the concerns often expressed are outlined below. A more detailed analysis of potential barriers was published by the King's Fund in a document called 'What's to stop us?' in December 2001. You can find this on the Kings Fund website www.kingsfund.org.uk

Concerns about patient involvement	
Patients might be anxious that	Staff might be anxious that
<ul style="list-style-type: none"> • their views will not be taken seriously • they will look foolish • they won't understand what is being talked about • they may cause offence if they are seen to complain • it might affect their treatment in the future 	<ul style="list-style-type: none"> • their work will be criticised • there will be unrealistic demands to change services • their role and authority might be undermined • the clinician/patient relationship might be affected • patients will lose confidence in them as practitioners if they are seen as vulnerable or not clear

Adapted from Fletcher G and Bradburn J, Voices in Action Resource Book, 2001

1.3 Involving patients in designing improvement

The aim is to generate activities which are inspired by collaborative learning, and which lead to demonstrable improvements in care and outcomes. As well as having the right to be involved, patients can help us make a better job of improving care than if we do it on our own, whether in choosing important topics or in designing better ways to work.

When asked why they get involved, patients give answers such as:

- "I believe I can make a difference"
- "feeling a part of a movement of change"
- "valuing and using our own experiences to bring about improvements"

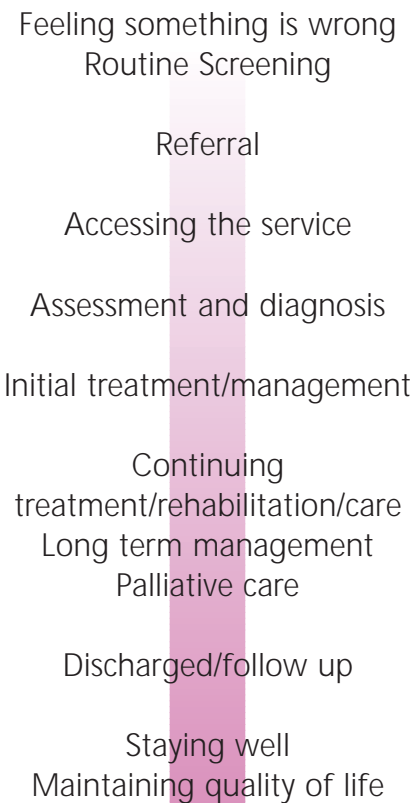
Voices in Action

People's health needs for using services vary a great deal. Different needs and different types of care may well require different approaches to involvement. The focus of attention might be a particular stage of the patient's journey through care, or it might be their whole experience. We need to consider the time before they gain access to the system, when they think something might be wrong but may, or may not, do something about it, as well as their experience following discharge or being supported to manage long term conditions. The diagram opposite illustrates a picture of a patient's journey through care, identifying stages that may be a focus for attention.

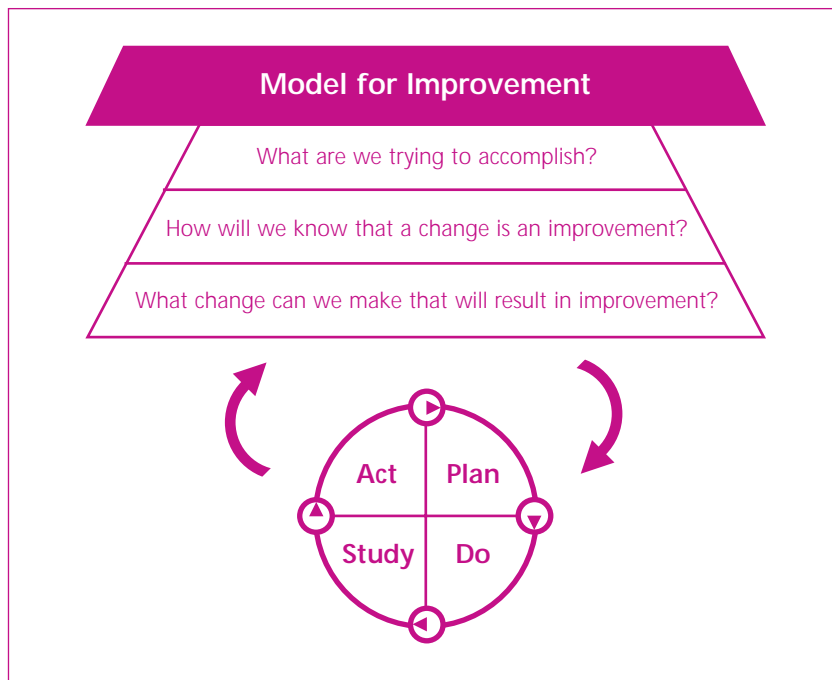
Patients should be involved at all stages of the improvement process, including discovering needs for improvement, designing improvements and learning from the outcomes of improvement efforts. Involvement is about truly creating working partnerships – not 'doing to' or even 'doing for' patients.

Agreed courses of action may be undertaken by patients themselves, by staff team members, or jointly by both, reinforcing the point that ideally everybody should be considered to be members of the same team.

A patient's possible journey through care



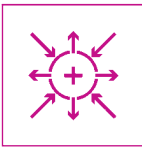
Any form of involvement must lead to demonstrable benefits to patients. The Improvement Leaders' Guide: Process mapping and analysis www.modern.nhs.uk/improvementguides describes how teams working together can redesign the processes to improve the care they provide. Using the Model for Improvement shown below, the aim becomes one of generating patient-inspired Plan-Do-Study-Act (PDSA) cycles of improvement, and more than this, seeking patients' active participation in PDSA cycles themselves.



Reference: Langley G, Nolan K, Nolan T, Norman C, Provost L, (1996), The improvement guide: a practical approach to enhancing organisational performance, Jossey Bass Publishers, San Francisco

What an experience. What a significant group of enthusiastic and committed colleagues - it was fantastic. It's a pleasure to see that patients are involved in the process - so often the patient has been ignored in the past, but the Collaborative is involving patients at all levels.

Patient attending Coronary Heart Disease workshop



2. Involving patients in every aspect of improvement

Involving patients in every aspect of improvement in a continuous and sustainable way will not be achieved overnight.

The diagram on the following page 'Involving patients at every stage', shows elements that are important in making progress towards this goal, together with some underlying questions. Although they are laid out as a cycle, bear in mind that it is possible to begin anywhere and that life is unlikely to be quite as simple as the cycle suggests. Nevertheless, if considered together with the following descriptions of each element, the model should provide a helpful guide to practical steps towards meaningful and effective patient involvement.

2.1 What are you trying to achieve?

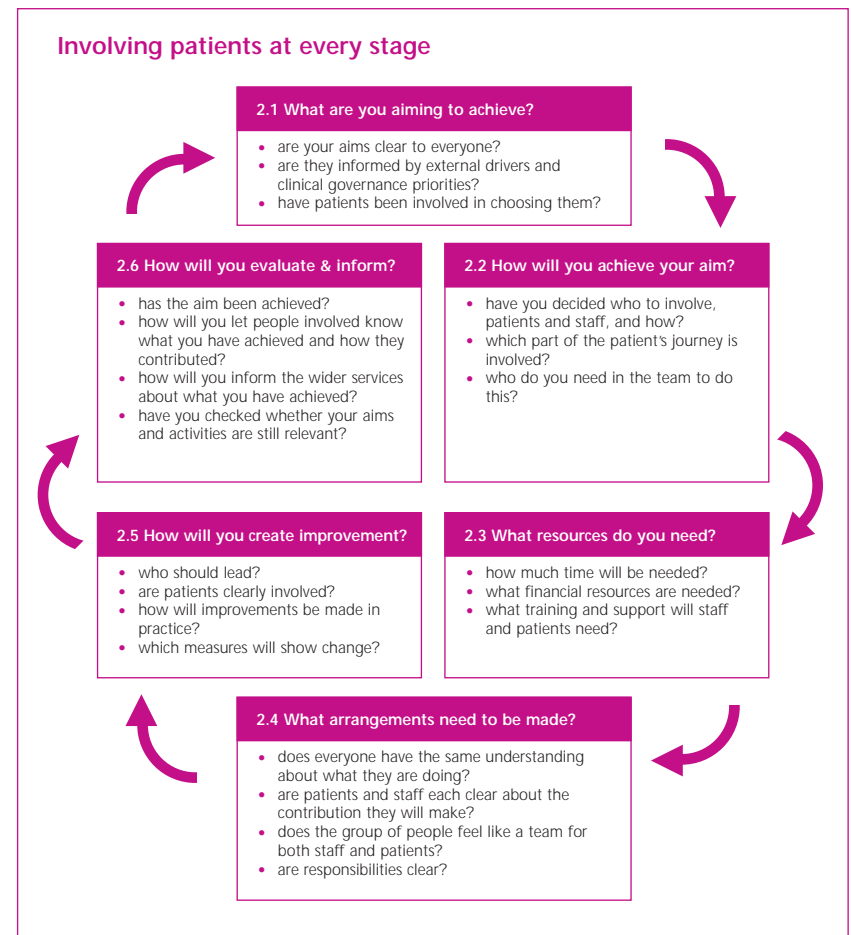
When deciding where to begin it is important both to take account of drivers from outside the organisation and to use knowledge from within. Patients should be involved in discussions about these priorities and decision-making about the aims. This could be done as a consultation project or by involving existing patient groups. Consultation that has been recently undertaken by other local health and social care agencies may also be a ready source of patient views to determine priorities.

Internal knowledge may include areas for improvement identified through clinical governance procedures. Other areas may have also been identified through previous involvement with patients. Individuals who can offer helpful views at this stage will probably already be known to service teams or could be identified through PALS (Patient Advisory Liaison Service).

To gain the support you need, it is crucial that chosen initiatives are felt to be important by key managers within the organisation, and that they understand how involving patients will help them achieve their own objectives. This requires a joint agreement on the focus and aims from the start.

2.2 How will you achieve your aim?

Consider the involvement approach that is most likely to help you achieve your aim, and is acceptable to all those involved. Patients, frontline and clinical staff and senior managers must all be included and must feel that what they are tackling is important if they are to commit time and resources to it. Different approaches may be needed for different stages of the patient's journey through care. It may be helpful to map this out if not already done. It may also be helpful to consider different approaches at different phases of the improvement process.



Patients and carers

Depending on the approach that has been agreed, patients can be involved by:

- gathering together a group for whom it is an area of particular concern
- contacting an existing group
- inviting individuals to join an improvement team
- going out to meet people or groups who might be interested

You also need to check whether individual patients want to be involved on a continuous basis or whether they may prefer to undertake a specific role and then hand on to someone else.

Frontline and clinical staff

Staff from all professions must be included from the beginning, so that they can contribute their own knowledge and experience and be part of the involvement process as well. This is important as it helps to build relationships and reduce anxieties. In addition, when patients and staff share their different knowledge and experience it can prove to be a catalyst for innovation and creativity. Issues relating to managing change are discussed in more depth in the Improvement Leaders' Guide: Managing the human dimensions of change www.modern.nhs.uk/improvementguides

Senior managers and clinicians

Don't forget to involve senior managers from the beginning. You will need their support for the changes that emerge.

2.3 What resources do you need?

Three things will need important consideration: time, finance, training and support. Talk to your Human Resources department who will be able to give you advice and support.

Time

Patients and staff who want to get involved will need to make a time commitment, but there should also be recognition that their time is precious. There may be naturally occurring 'life cycles' for different aspects, and it is helpful to try and identify what these may be. This will provide those involved with some idea of what their commitment will be, initially at least, and when they may be able to hand on to someone else if they wish. This makes an important contribution to maintaining energy and enthusiasm.

Finance

There is advantage in making sure that adequate finance to support patient involvement is clearly identified and placed in a separate budget. Expenses as these can be significant and include not only expenses for travel and cover for care but also for sundries such as stationery.

It is particularly important to be sensitive to financial arrangements for patients, since it is inappropriate for them to be the only ones involved who are not being paid: especially if they have had to take time off work, or are on benefits or pensions. These issues should be discussed with patients at the outset. Make it clear that their commitment and input is not taken for granted, that their involvement is treated seriously and that it will be followed through to achieve results.

A facilitator may be needed at various times and potential costs should be taken into account.

Training and support

The training and support needed for the patients and staff involved should be clearly identified and steps taken to ensure that it is made available. It may be helpful to nominate a senior manager within the Trust to take responsibility for this.

Don't underestimate the amount of time it can take to build relationships across boundaries and change culture in readiness for improvement. For more information go to the Improvement Leaders' Guides: Working in systems and Building and nurturing an improvement culture www.modern.nhs.uk/improvementguides

2.4 What arrangements need to be made?

Once decisions about what approach to use have been made and the resource issues have been addressed, it is important to make practical arrangements. Make sure everybody who needs to know has been informed, even if they are not directly involved. It must be clear who is leading any particular initiative, and they must be given appropriate support to undertake this extra role. Careful planning is needed to ensure that meetings or workshops are held when people are available and that consent and ethical approval, if necessary, have been obtained in advance. Arrangements need to be made for reflecting on what has been learned about the service, sharing it with other key people and identifying specific improvement opportunities.

Remit	<ul style="list-style-type: none"> • does the group have clear terms of reference? • does everyone have a copy? • has the meaning been discussed so that everyone has the same understanding of what they are there to do? <p>If not, people may be 'travelling' in different directions and working at cross-purposes</p>
Role	<ul style="list-style-type: none"> • is each member clear about their particular role? • what contribution does each person think they are able to offer? • what do other people think the roles are? <p>People may make assumptions about the roles of the different group members based on the professional's title, or the group or voluntary organisation that the person belongs to. Be very clear about if you want them to be a representative of their organisation or group, e.g. a GP to represent all the GPs in the practice, or if they are each just bringing their individual and unique patient or health professional perspective to the discussions</p>
Relationships	<ul style="list-style-type: none"> • does the group feel like a working team? • do people share a common purpose and goals? Have they ever been discussed? • do you know each other as people, or are you strangers bound by your roles? <p>It will make a difference to how open and honest people are able to be about the issues they are discussing and may well influence the way decisions are made. Look at the Improvement Leaders' Guide: Managing the human dimensions of change www.modern.nhs.uk/improvementguides</p>
Responsibilities	<ul style="list-style-type: none"> • what is the group responsible for and to whom? • is the group clear about issues of responsibility, or is it all left to the chairperson? • does the whole group take responsibility for seeking user views, putting items on the agenda, and ensuring that members have sufficient information for discussions and decisions? • how are decisions implemented? • is the group clear how decisions that they make are fed into the wider change agenda within the Trust, health community or Strategic Health Authority? <p>If you are not clear, it might be helpful to do a mapping exercise to see where the lines of communication from your group go. How does your group fit with other groups/committees who are also working on service improvement?</p>

There are many different ways of working with patients. Formal methods include working as part of multidisciplinary team or group and meeting on a regular basis. Less formally, you might meet people in the community, perhaps on a one-off basis. Each has its place in contributing to effective patient involvement. If you are engaging with patients in a formalised way, such as inviting them to join a steering group or committee, it is important to pay attention to key factors such as **remit, role, relationships and responsibilities**, as in the table opposite. This will enable the everyone to get off to a sound start and to work more effectively together.

2.5 How will you create improvement?

Once you have identified areas where changes might lead to improvement, you need to test them out in practice. These changes may be at different levels of service delivery, but generally speaking it is considered sensible to keep them small and implement them quickly. This allows rapid learning and maintains energy and enthusiasm. The Improvement Leaders' Guides: Process mapping, analysis and redesign and Matching capacity and demand provide advice and ideas. www.modern.nhs.uk/improvementguides

Patients should continue to be involved as team members throughout all stages of any improvement process. It is probably more helpful to think of continuous patient involvement and continuous improvement as being the same thing. We are no longer merely thinking of projects with a beginning, middle and end. Rather, we have ongoing processes of improvement that rely on continuous testing of change ideas and feedback of results that can be used to plan further improvement cycles.

Building in simple measures is crucial to success. Ways to do this are described in the Improvement Leaders' Guide: Measurement for improvement www.modern.nhs.uk/improvementguides. Measurement should be planned from the beginning as part of the improvement process. Patients should be involved to ensure that the measures chosen will provide feedback that will be meaningful and helpful to all those involved.

Your challenge is to establish continuous improvement as part of everyday practice in such ways that patient involvement is seen as a key component



2.6 How will you evaluate and inform?

It is important to evaluate what has been done. Measures to show whether you have been effective in creating improvements should be built into the improvement process itself, as mentioned previously.

It is equally important to check out regularly how patient involvement is working, from the point of view of both patients and staff. One measure will of course be the demonstrable improvements in services that are a direct result of shared working and learning. However, there will also be less tangible outcomes and it is important to consider these too. For example, it will be helpful if those involved, patients and staff, keep a brief ongoing log of their experiences. From time to time opportunities should be provided to reflect on these experiences and build a portfolio of learning that will strengthen patient involvement in the future.

Informing all those who have been involved and may have been affected is also key. This is particularly important for patients. People will only give their time and energy if they can see that their efforts have resulted in some positive changes. Producing evidence that this has happened, and informing people of your findings and results, is a key part of the process. If this is done well, it will provide a stepping stone for further involvement. If not, it will become increasingly hard to involve people in the future.

Finally, it is important to look up at the broader picture at regular intervals and to check that current priorities and activity are still relevant. In other words, go back to the first step and check whether what you are aiming to achieve is still appropriate in current circumstances, or whether it needs adjusting. Patients should of course be involved in this check against reality.

For more information look at the Improvement Leaders' Guide: Evaluating improvement www.modern.nhs.uk/improvementguides

3. Stories of involvement: listening, dialogue and observation

3.1 Gaining systematic feedback from patients to improve care in general practice

The context

Four Primary Care Trusts in the South West invited their general practices to carry out a systematic patient feedback exercise. Seventy-five practices agreed to take part, involving about 250 GPs and nurses. These practices were encouraged to invite a small, selected group of patients, known as 'critical friends', to help discuss the practice's results and find solutions for redesigning the service from a patient's perspective.

The aim

To provide an opportunity for general practices to seek patients' views about the quality of their service, and to identify patient-centred improvements.

What was done?

A one-page survey questionnaire was given to patients on-site after they had seen the doctor or nurse. It asks patients to simply rate various aspects of their general practice care such as:

- making an appointment
- availability of staff
- quality of the consultation
- reception staff manner
- extent of information provided by the practice

Completed questionnaires were returned to an independent external organisation, which processed the data and returned private and confidential results to each practice. This included benchmark data to allow comparison against other general practices. The use of these results in one practice to improve its general care and patients' experience of consultation with a GP is described over the page.

Improving general care in the practice

About a month after the practice received its results, patients were invited to discuss them. Since trust is at the heart of quality improvement, it was felt best for the practice to select patients they trusted, and with whom they could develop a partnership in the interests of improving the quality their service. These patients formed a group of 'critical friends' (see section 5.6).

What were the outcomes?

The practice scored quite low on 'waiting time in the surgery'. When practice staff met with patients they were quick to point out that 'waiting time' was a very difficult aspect of quality to improve. "It's just the nature of the service," commented the practice manager. However, one of the patients, who had read all the patient feedback, commented that it appeared that it wasn't the waiting that was the problem, but not being told how long they would wait. This left patients feeling they were not valued. The practice manager was still quite defensive, and said they did tell patients how long they would have to wait. On further questioning by the patient, however, it became clear that this only occurred when patients asked and the receptionist revealed that patients rarely did so.

One of the other patients suggested that perhaps telling patients how long they would be waiting could be done on a more proactive basis. This was agreed as a new initiative to be undertaken by receptionists at that practice.

What was learned?

- it is important to seek patient views in a systematic way so that practices can compare themselves to others
- having patients present to discuss the results ensures that planned redesign of services is patient-centred and patients can help in finding practical solutions
- dialogue between staff and patients is at the heart of partnership

Focusing on one GP's consultations

The questionnaire contains a section on the patient's experience of the consultation. Confidential feedback can be provided to an individual GP or nurse about their communication skills within the consultation, for the purpose of reflection and as an aid to appraisal.

What were the outcomes?

Patient ratings of one GP's communication skills were slightly below average compared to national benchmarks. In particular his score on 'explanations' was low, and some written comments mentioned his 'medicalised' language that undermined the patient/doctor relationship. The GP was unaware that patients felt this way. After discussions with trusted colleagues, he decided to attend a workshop on communication skills. One of the key skills he learned here was active listening and making reflective summary statements.

What was learned?

- no-one is ever quite sure about one's own communication skills until someone else, in this case patients, are able to comment on them
- patient feedback was welcomed and constructive
- communicating to patients is a skill that can be taught and learned

3.2 Learning from carers about how to improve aspects of palliative care

The context

This was a project within a Primary Care Trust to improve drug-related care for people over the age of 21 who required palliative symptom control.

The aim

To find out the views of patients and carers on medicines management in palliative care and what could be done to support them and to improve the service.

What was done?

Interviews were carried out with carers who had been recently bereaved. Following a discussion with the local hospice, it was suggested that it was probably more sensitive to interview the carers about their experiences than patients in the terminal stages of disease. The carers were invited to participate by the hospice and first names and contact numbers of three people were given to the interviewer. No details of the patients' clinical histories were disclosed. Three separate interviews were carried out in the carers' homes, each lasting about an hour. The interviews were recorded in note form by the interviewer and later transcribed and compared for common themes.

What were the outcomes?

Two of the common themes that emerged were that patients and their carers had been concerned about the use of morphine and the introduction of a syringe driver. Leaflets were developed, in conjunction with the carers, patients and healthcare professionals, to cover these topics.

Another issue arose about pharmacy registration. So a questionnaire was developed to find out whether patients would like to be registered with a particular pharmacy. This was developed with a small group of patients before asking a wider group of users.

What was learned?

- the amount of valuable data and information from a small sample
- the importance of setting the context with the interviewee and being clear about the scope, ability and resources needed
- note taking is not always the best way to record dialogue as it is difficult to listen and write at the same time. Either ask permission for the session to be taped or take a colleague with you

3.3 Creating user and carer champions in mental health services

The context

A review of mental health services in the South East has resulted in a new way of delivering services by an integrated health and social services Trust.

The aim

To improve access for carers, users and staff, and improve carers' and users' experience across all boundaries in health and social care

Who was involved?

Health, social services, voluntary sector, frontline staff, service users and carers.

What was done?

The most significant feature of the project was developing new roles of 'user and carer champions' as equal members of the project team. Their experience and expertise has made a vital contribution, enhancing the process and outcomes. Brief accounts from two of them are on the following pages.

Thoughts from a service user champion

I am the service user champion at the local modernisation group. My role involves championing the cause of user requirements and actively liaising between service users, the carer champion and statutory and non-statutory services.

So what's the difference between a user representative and my fancy new title? The authority and recognition that the group has given to my role since they created it. They recognise that I have a duty to the service users in my community, and that when I insist on something, it is because I believe that it is what the users want and need. And in general, it is accommodated – even if it wasn't part of the original plan.

I am also given access to the project subgroups I need to be on, instead of being elegantly sidelined. There have been times when user reps have been put onto subgroups that effectively do nothing, but do it splendidly!

The group realised from the outset that the other model of passive, user/carers involvement that was used could not work in a pro-active group. We had to design a completely new model. The group effectively said to me; "You know what we need to achieve in terms of effective group working. Work out how you can help us to achieve that". In other words, a blank sheet.

There is no 'them and us' situation in which I take 'the user stance and position' in the group, and others take 'the professional stance and position'. We knew at the outset that we had to work without barriers between us and that things like administrative support had to be accessible to us all. This has been a culture shock for me, and I have had to adjust my method of working from being confrontational and expecting a fight, to working cooperatively.

Part of the change from the culture of traditional user involvement has been to work more closely with the carers' champion. I have discovered that whilst our agendas are not identical, they are much closer than even I thought.

Thoughts from a carer champion

Why me?

- my wife and I have been carers for thirteen years for our younger daughter, who is diagnosed with severe and enduring mental illness
- we have been active members of the national schizophrenia fellowship for 12 years and ongoing joint local group voluntary co-ordinators for two years
- retirement has given me the essential spare time for this intensive group work

Starting point

- our local reference group has fully embraced the requirement set out in the National Standards Framework (mental health) for service user and carer champions to be involved in modernising our mental health services
- our participation within the group is as active members
- the constant message has been to keep the aims and objectives of intended improvements as simple as possible, with the emphasis on achievement. This is actually the same advice given to a service user recovering from severe mental illness!
- the Plan, Do, Study, Act (PDSA) cycle is our selected tool to achieve improvement
- the implementation of modernising our services has to be staged
- the remit for the champions is essentially complementary and we have met several times, in addition to the full group meetings, to execute PDSA plans

Improvements made

We did not have to scratch too deeply to identify where the joint duty system had developed bottlenecks, wasting valuable time and frustrating the team, service users, carers and other professionals. It has been rewarding to witness the enthusiasm of the Joint Duty Service Teams in testing, reporting back, modifying, re-testing and implementing the cycles

Challenges faced

- informed carers and service users fully realise that to deliver the required integrated service provision outlined in the National Service Framework is a mammoth task
- we have all recognised the difficulties that dedicated community mental health staff have faced. Working as a team is not easy when you have different employers, line management, working practices, separate funding and so on
- it has been challenging for the service user and the carer champions as well as the professionals to sit down together and build bridges of common understanding

Lessons learnt

- there have been times when we have risked being overloaded. I guess there is always a danger of this when others see a method of improvement working successfully. The solution is of course to pass on to others the knowledge of how to use the tool
- the benefits of having service user and carer champions actively involved in modernisation have been proven

Next steps

The champions' work is far from over. Many additional PDSA cycles have been identified in addition to improving the joint duty system and work on these is on going.

The Model for Improvement has been used to design and evaluate the change efforts made and Process mapping has proved a powerful tool to aid understanding of the real causes of problems experienced by users, carers and staff.

What were the outcomes?

Improvements made include:

- service users involved in agreeing their appointments
- better communication, screening and risk assessment
- development of an integrated waiting list
- improvement of a joint duty system with social services
- jointly owned documentation
- reduction in DNA rate

3.4 The breast cancer journey: improving patients' experience

The context

This story tells how a cancer network in the South West used a patient and staff information-mapping workshop to improve the way that local breast cancer services and the services for other cancer patients are organised and delivered.

The aim

To provide an informal forum to discuss ways of improving local breast cancer services. Discussion initially centred on written patient information, although it was hoped that this would lead to the exploration of other issues that impacted on patients' experiences across the whole cancer journey.

Key themes for exploration included what patients needed from the breast cancer services in the future and how current shortcomings could be addressed.

Who was involved?

Patients, carers and staff, including the senior breast care nurse, consultant breast surgeon, superintendent radiotherapy radiographer, breast clinic co-ordinator, staff from the mammography unit, hospital wards and the out-patient department. There were additional contributions from the Radiology and Network Oncology Centre.

What was done?

Patients were initially contacted by telephone by one of the breast care nurses. Those who expressed an interest were provided with further information. Seven patients and one male carer attended.

Staff from different departments were sent invitations and were requested to forward copies of all information which they sent or gave to patients, including appointment letters, locally produced information leaflets and other frequently used information materials. Twelve members of staff were present on the day.

For the first hour patients worked with the senior breast care nurse, discussing core issues about their experience of the service and its impact on them. Staff worked in a parallel group exploring the provision of patient information across the care pathway.

Following tea everyone met in a single facilitated group to discuss the topics that had arisen. Staff heard at first hand about the issues that had affected the patients' experiences and were able to respond to specific queries or concerns. The discussion was scheduled to last for an hour, but continued beyond this because of the motivation and interest of both staff and patients.

Key points were recorded on flipcharts and included information across the care pathway, training needs of non-specialist breast care nurses on wards and in primary care, and waits for chemotherapy.

What were the outcomes?

Shortly after the workshop, a report summarising the key issues and a proposal for how these might be addressed was sent to all participants. The senior breast care nurse undertook to ensure that they were followed up. All the issues highlighted have been acted upon since the workshop. A review meeting involving key members of staff has been held since the workshop.

3.5 'I'm not a lot of people, I'm me.': using the 'patients as teachers' approach

The context

The 'patients as teachers' approach was used to identify ways to improve care in the cardiac department of an acute hospital in the South East. Previous attempts to focus on the concept of the patient as a 'consumer' had led to both patients and staff viewing it as a 'naming and shaming' exercise.

The aim

To test the assumption that patients' direct experiences of NHS services make them best placed to teach the NHS about improving those services.

Who was involved?

Patient involvement came from those who had recently received treatment and were willing to participate. 250 patients were approached, of whom 50 agreed to take part, with a further 50 agreeing to act as observers.

What was done?

The proposal came from the director of nursing and quality and there was an independent facilitator.

Three focus groups (see section 5.1) were set up to first pool their experiences of the service and then to meet with staff to discuss issues seen by both groups to be of high importance.

Using a topic guide produced for the purpose, the patient focus groups were encouraged to be open in sharing experiences with staff, whether good or bad. The groups were then asked to describe what they felt made a good quality service, and to explore the themes that emerged. Transcripts of the discussions were made for later analysis.

Two staff workshops were held at the same time as the patient focus groups. One was for senior staff, to stress the potential benefits of the process; the other for the clinicians and managers associated with the cardiac service. The workshops prepared staff for feedback sessions with patients and involved them in describing their own priorities for an excellent service. Themes emerged that were common to both patients and staff, such as the importance of good staff attitudes and understanding, and concern about waiting times. Ten patients volunteered to highlight the issues raised in their focus groups with 30 clinicians and managers in a joint feedback session. Following a powerful presentation from a number of patient representatives, describing their own and others' experiences, the meeting split into four groups to focus on actions that could be taken to improve services. These actions were incorporated into an agreed plan that was later circulated to all programme participants.

What were the outcomes?

The focus groups produced a wealth of material about patients' experiences. Many felt that the service they received was 'one size fits all', rather than being tailored to their needs. Their views about the way the department was run were also revealing. One said: "Nurses don't have time to do their jobs properly, because they are so involved with things that aren't really down to them."

One very real concern of patients was the staff's attitude towards them, with one pointing out that "staff were talking about their pay rise and how much overtime they had done. That seemed to come before patient care".

A number of positive changes were made to the cardiac service as a result of the programme. For example, an additional cardiac rehabilitation nurse post was funded, and hospital-based rehabilitation expanded. But perhaps most importantly, staff were encouraged to develop their communication skills and to listen to the views and experiences of patients.

What was learned?

- turning patients into teachers is not a quick fix: it requires investment in time and resources as well as an independent facilitator
 - a relatively formal process needs to be followed: basic ground rules such as confidentiality, communication and sticking to timescales are critical
 - given the right environment, patients can make excellent teachers.
- This is perhaps the key learning point

3.6 Patient involvement in cardiology service improvement

The context

A Trust in the South West developed a service improvement approach called 'The Patient Care Development Programme'.

The aim

To enable teams of clinical staff to interview patients in their own homes and to use the information to improve services.

Who was involved?

A multidisciplinary team of cardiology staff was formed, including nurses, cardiac technicians and doctors.

What was done?

The team identified a key issue from the views of both patients and staff. This was about providing follow-up and further support for cardiology patients after discharge from hospital.

To address this need, the team looked at guidelines and best practice from elsewhere. They applied to the British Heart Foundation (BHF) to fund a specialist nurse post. The bid was successful, and once the nurse had been in her job for a year, the post was evaluated. This was done in two ways:

- a quantitative approach. Data was gathered about the numbers of patients seen and changes that had been achieved in key areas of risk such as reducing cholesterol levels, lowering blood pressure and giving up smoking
- a qualitative evaluation. A sample of 25 patients visited by the nurse were interviewed over the telephone. The transcripts of the interviews were subjected to a thematic analysis

What were the outcomes?

- an interview quote describes the general approach taken by the BHF nurse, of information-giving followed by reassurance: “What was most helpful initially was the information, but then as I got to know her I realised I could say anything to her and she was entirely sympathetic and understanding.”
- the importance of giving patients and their families the opportunity to take important information on board in their own time was emphasised: “You don’t really take anything in until you get home – even if they do tell you things when you’re in hospital you don’t take it in.”
- providing continuity of care and ensuring that people don’t ‘fall through the net’ was another role that was highly valued: “She provided continuity. She picked me up after I was discharged. I had an angioplasty in the end – I didn’t need an operation.”
- the quantitative measures showed that the post holder had been successful in meeting targets set for numbers of visits made and risk factors reduced
- the qualitative evaluation showed that the input received was highly valued
- the majority of patients said that they would not hesitate to contact the BHF nurse in the future should they require further input

What was learned?

- that quantitative and qualitative measures used together can fully describe the impact of service improvements
- involving patients in needs assessment and evaluating the impact of changes provided a much more detailed picture of what was needed and what had been achieved

3.7 Using a patient group in orthopaedic services to support others and to generate ideas for improvement

The context

Patients undergoing major joint replacement in a Trust in Northern England received systematic and formalised support from a range of professionals throughout their journey. Patient surveys and studies indicated a high level of satisfaction, but it was thought more that could be done. The team wanted to have regular contact with a group of patients who have had a joint replacement, so that they could tell them how the service could be improved. They were particularly interested in developing a network of people who could help prospective joint replacement patients by giving them informal and very practical information about what they can expect prior to and post surgery.

The aims

- to provide informal peer support and reassurance for patients about to undergo joint replacement, and to provide an ongoing support network for patients who have had joint replacement surgery
- to act as a sounding board when agreeing the next steps
- to actively develop information and other support material for patients
- to provide practical advice and tips to patients about post-surgery life

What was done?

Advertising was done through flyers and advertising at outpatient clinics and on the ward. Potential participants were invited to an initial meeting, facilitated by members of the orthopaedic team, which was also attended by the secretary of an already established patient group from nearby. The group identified a secretary and treasurer and recruited one of the orthopaedic consultants as president.

It quickly became clear that there was an appetite amongst the group to ‘give something back’ to their local hospital and specifically the orthopaedic service. Group members recognised the potential benefit for prospective joint replacement patients having an opportunity to speak to people who had personal experience of joint replacement.

What were the outcomes?

- The group now meets monthly, providing a peer-support forum for patients, and has:
- arranged a programme of open evenings for patients waiting for surgery, to offer practical pre and post surgery advice
 - generated ideas for service improvement, particularly informing development of combined occupational therapy and physiotherapy pre-operative assessment
 - designed and advised on patient information leaflets and questionnaires

What was learned?

- this is a very successful and practical approach to user involvement that will provide an ongoing and rich source of help and advice in the delivery and improvement of joint replacement services
- we should not underestimate the willingness of patients to get involved and provide help

3.8 Using 'discovery interviews' to improve the way a cardiac service meets its patients' needs

The context

A network for Coronary Heart Disease is using patient narrative to improve experience and outcomes for patients with confirmed or suspected coronary heart disease and their carers (see section 5.5).

The aim

To build improvements into cardiac service delivery by learning from patients with coronary heart disease, and their carers, about issues of importance to them.

Who was involved?

Patients at different stages of coronary heart disease, and their carers, were interviewed separately using semi-structured 'discovery interviews' to learn about the impact of their illness on their lives. A health professional involved in the patient's care or treatment invited them to participate and provided a pack with further details. If they returned a reply slip, indicating an interest, the participant was contacted by the interviewer to arrange the date and time of interview.

What was done?

Interviews took place in the patient's home and lasted usually for around an hour. They were tape recorded and later transcribed by the interviewer. Following removal of identifiable material, the transcripts were shared with clinical teams to help generate ideas around service improvements that reflected patient needs.

What were the outcomes?

An interview with a patient following cardiac surgery identified a need for more certainty about appropriate levels of activity following discharge from hospital: "I felt a lack physio people. Although there were dozens of them, they didn't say what would help me breathe or 'this is the exercise you could do'. I'd have liked more information about that but I didn't get it."

This patient's transcript was shared with the cardiac rehabilitation project team, and helped the physiotherapy team identify a different way of working with post-operative patients. A series of PDSA cycles have been used to test ways to match this patient's previously unmet need. The testing cycles included the pilot

of a post-operative exercise talk by the cardiac rehabilitation physiotherapists. Following feedback from the first session, the time of day was changed to accommodate family and partners' availability, to ensure that they had the opportunity to ask questions and prepare for the return home of the patient. Patients were actively encouraged to invite their 'informal carers'. An invitation slip to the exercise talk was also developed.

What was learned?

- patients appreciate the opportunity to be able to tell their story as a way of formal 'closure' of the episode
- the advantages of using this simple approach to draw out valuable information from the patient's perspective, and the richness of this compared to other survey methods
- discovery interviews can provide clinical teams with a realistic way of making improvements that are sensitive to the needs of patients

3.9 Using patient shadowing to identify where improvements are needed

The context

As part of the re-design of a colposcopy service in the Home Counties, patient shadowing (see section 5.3) was used to identify possible areas of improvement from the patients' perspective.

The aim

To collect information about a number of factors including:

- actual time spent waiting or being seen
- the standard of verbal, printed and signposted information given
- staff responses to questions and specific needs, e.g. disability
- the ambience of each area visited
- specific points mentioned by patients and staff

What was done?

During a three-week period, each of three surgeons had clinics shadowed. The clinic nurse approached patients. She explained about shadowing and gave them the information sheet. The forms used do not identify patients or have specific dates to identify the clinic. If the patient agreed, the shadower introduced themselves and ensured the patient understood what would happen. They made it clear that at any time they could ask the shadower to stop. The shadower asked appropriate questions and waited with the patient, following them wherever they went.

During the consultation or procedure the shadower either remained in the waiting area or discreetly in the background, observing. After each activity, such as briefing by the nurse or consultation with the doctor, the shadower asked for the patient's reactions to what had happened. They collected relevant information in a concise way and did not reject apparently minor problems. The patient was able to see what the shadower was writing if they wanted. When the appointment finished, the shadower asked general questions on what could be done better and what was particularly good, and provided an opportunity for the patient to add anything they chose. After the patient left, the shadower added his or her own comments in the box provided. Clinic staff comments were also recorded.

What were the outcomes?

Patients mentioned

- the length of waiting time in outpatients and for appointments
- that a 'pessaries' label was easily visible causing patients to think it was part of their treatment
- the need for a recovery area as patients did not always feel ready to drive home immediately after treatment.
- they wanted some way of obtaining refreshments without walking outside the building

Staff highlighted

- conversations in side rooms can be heard in the treatment room
- the consultant has to wait while patient is with nurse before and after treatment

Changes made as a result of patient shadowing

- music is now played in the waiting area and in the colposcopy room
- the 'pessaries' label has been removed
- the appointment system has been redesigned, to include pooled referrals and partial booking
- the colposcopy unit has been sound proofed
- a second nurse in clinic means that the doctor is not kept waiting and more patients are now seen

What was learned?

- patients are aware of many things that staff are not

3.10 Involving patients and carers in role redesign in diabetes care in two Trusts in central England

The context

Diabetics case was looked at in two 'typical' towns in England, with 'typical' health services, but quite different demographics.

The aim

To hear from patients and carers at all levels and at all stages of the process about the existing service, how it could be improved and also their thoughts and feelings on role changes.

Who was involved?

The diabetes care teams, GPs, practice nurses, district nurses, other healthcare workers involved in diabetes care and users of the diabetes service, patients and carers were all involved.

What was done?

Each site has a carefully established management structure to provide direction and undertake detailed testing of each role. Patients and carers are involved at each level and in all activities. Patients have been involved in workshops, questionnaires and focus groups:

- workshops: 80 patients were chosen at random from the local diabetes register and invited by letter. Posters and leaflets were distributed by diabetes specialist nurses and also through the Diabetes Centre where patients go for information and education. The workshops were used to explain the purpose of the pilot and provide the patients with reassurance that it would not reduce the quality of their care. We solicited views from those attending and gave them an opportunity to tell their own stories and to ask questions
- questionnaires: a questionnaire devised by the project team was distributed to around 2,500 patients by frontline primary and secondary care staff. The questionnaires are anonymous and confidential and are returned to a Freepost address
- focus groups: are especially useful for accessing patients from ethnic minority groups, whose first language is not English, or who might have poor literacy skills. These are arranged at community centres and involve link workers and community representatives to engage the community as well as resolve language difficulties
- shadowing: a number of patients were followed throughout their visits to see the service through their eyes

Getting deeper involvement

We identified patients who would be willing and able to become more actively involved, through the workshops and by approaching the local user support groups. Support group representatives provide their own views as users of the service as well as the views of the wider user group and in turn can provide useful feedback to patients and carers about progress. There is also wider, but shorter term involvement from other patients and carers through:

- process mapping workshops, at which patients and carers helped to identify main problem areas for patients and contributed useful ideas for the team to explore in redesigning roles
- a role redesign workshop involving patients and carers, using the changing workforce toolkit for local change
- active involvement with the design and small scale testing using PDSA cycles of the new roles, and contributing appropriate professional advice e.g. on education, as well as the patients' perspective

What were the outcomes?

The pilots are ongoing, and patients remain involved in developing the new roles with the possibility that they may be recruited into them.

What was learned?

- be sensitive to community and cultural issues: there was a poor turnout to workshops that were put on during Ramadan
- be mindful of all the extra expenses, not just travel, incurred by patient representatives who do not have access to the NHS office facilities
- remember that they are people who have interests, skills and expertise to contribute beyond their experience of being a patient or carer
- don't forget the counter-balance of the staff perspective: all of the above exercises have involved both patients and staff

3.11 Involving users in clinical governance

The context

Users actively influence and shape their clinical governance agenda in this Mental Health Service and, when asked, they said they were confused about who was looking after them and had difficulty remembering contact phone numbers especially in times of crisis. No written information was given to users and carers on discharge.

The aim

To improve the quality and effectiveness of discharge planning from the inpatient unit.

Who was involved?

- a steering group for clinical governance: senior nurse, locality director and consultant psychiatrist
- mental health users and staff
- SUNNY-Service Users meeting which covers the North and Northern and Yorkshire. This is an independent group which sit on operational and planning meetings to influence governance arrangements
- local mental health forum of service users and voluntary groups

What was done?

Service users' views around discharge information planning were explored by the steering group using face to face interviews. They jointly developed a questionnaire that was used by two service users at each of the inpatient units. This revealed that only 50% of patients knew the name of their care coordinator and had met them prior to discharge.

What were the outcomes?

A user suggested creating a credit-card sized 'crisis card' to provide contact information for the care co-ordinator, GP, social service and helplines. Users were involved in the design and decision making, and suggested it should not have a mental health services logo and should be tailored to individual needs.

Now

- 'crisis cards' have been introduced for all patients discharged from the inpatient unit
- users and carers are more confident and feel less stressed especially in times of crisis since they can ask someone to phone without having to remember the details. The path to care is smoother, quicker and less traumatic
- all staff in the hospital ward and community services were told about the card and they now meet together to plan for patients' discharges
- work is in hand, supported by the local service users network, to extend the idea of crisis cards across the whole service and other mental health units are adopting the idea

What was learned?

Involving users goes beyond asking what they want. They can also design and create simple, inexpensive solutions that meet their needs better.



4. Strengthening patient involvement

The rapid growth of patient involvement across the NHS has already been mentioned, as has its potential complexity. This raises the challenge of how to ensure that at some time in the future we do not look back wistfully at a 'flavour of the month' that has become a distant memory. If the investment of effort by all those currently involved is to achieve sustainable benefits, we need to explore how to build patient involvement into daily work within NHS Trusts.

Included below is a list of key questions which, if addressed, will help you develop continuous and effective patient involvement

- does the Trust have a patient involvement strategy, linked to its improvement priorities, with designated responsibilities allocated to board members?
- do senior managers and planners routinely build patient and carer involvement into strategy and the core business of the organisation and into core clinical governance activity with appropriate resources, designated budgets and protected time identified?
- is patient and carer involvement included as part of regular job descriptions and accountabilities, not just special staff doing special projects? Is it built into organisational structures and management reporting mechanisms?
- is the Trust developing its capability by helping all those involved to develop the necessary knowledge and skills, and by providing support?
- are monitoring procedures in place to safeguard quality, ensure demands on time remain manageable and to avoid 'involvement fatigue' caused by patients receiving multiple requests from different departments?
- is there a central process to create links to other appropriate 'bodies' and to ensure joined-up working and sharing of learning across the Trust?



5. Methods for involving patients

5.1 Focus groups

Description

A focus group is an informal group of people who share common characteristics, who meet to discuss and share their experiences about a specific topic or problem. They could, for example, be people with the same disease, e.g. arthritis, or people who have made a recent visit to accident and emergency. Group membership should aim for a good mix of people in relation to the topic and should also consider other aspects including age, culture, ethnicity, gender, geography, level of disease or disability.

Group members can be recruited by contacting a variety of agencies, including voluntary and statutory organisations, healthcare professionals, self-help groups and local media. A letter of invitation may be used to target certain groups explaining the process, proposed objectives and the time commitment to the project. It is likely that between 12% and 25% of those contacted will respond – consider this when deciding how many letters to circulate.

A focus group usually lasts between one and two hours, is facilitated and uses prepared questions and themes relating to the topic for discussion. It is helpful if an observer can support the facilitator.

When to use

- to find a wide range of experiences around specific topics with different sections of the community
- to find new information from participants' views

Advice

- establish how you will fund expenses before setting up the group
- clarify topic, purpose, objectives and outcomes before recruiting people
- send a screening questionnaire to those responding to invitation
- group members could be new to focus groups but should have knowledge or experience relevant to the topic
- groups should comprise 6 to 12 people
- find a comfortable, neutral venue which is accessible to all participants
- agree ground rules and a timetable with the group
- facilitation should be by someone not directly related to the project
- check beforehand to see if members of the group need additional support, e.g. people who are not able to read, hear, see or speak English

- record all discussion in the group and feed back progress and achievements to participants
- provide refreshments

Reference

Morgan, D and Krenger, RA (1998) *The Focus Group Toolkit*, Sage Publications

5.2 Patient as Teacher

Description

Patient as Teacher is a two stage process involving representatives from patient focus groups meeting professionals to discuss what works from their own point of view and make recommendations for service improvement.

The aims of the process are:

- to identify what good practice looks like from the users' points of view
- for recommendations for improvement to be made
- for users to teach clinicians in a supportive environment
- for mutually agreed outcomes to be monitored against

Current research is suggesting that it has a significant effect on clinician behaviour at six months. In addition:

- patients enjoy it
- it generates user-defined outcomes that can be monitored
- the main cost is facilitation

Stage 1: facilitated focus groups of patients, all of whom suffer from the condition, are asked questions to enable discussions on what has worked for them in managing their illness and to offer suggestions as to how the service could be improved.

Stage 2: self-selected delegates from the focus groups are identified. They are asked not to speak about their personal experiences, but to represent the views of those in their group. They then meet with clinicians: consultants, registrars, nurses, AHPs, GPs and 'teach' them good practice from the patients' point of view and share with them the suggestions for service improvement. A plan is agreed and staff select which actions they would like to take forward.

When to use

- for improving the care and experience for any chronic illness where users have had a long contact with the service
- education and training of clinical staff

Hints and Tips

The facilitator needs to ensure that the patients, not the professionals, lead the meeting:

- hold the focus group meetings at an appropriate location for patients preferably in a community setting and at a suitable time for them
- use staff not connected with the particular service to organise and facilitate the focus group to ensure impartiality. PALS staff can be very helpful
- one or two members of the service team will need to be present to answer questions and provide clarification
- the patient volunteers who are going to present to the clinicians will need good preparation and support, allow one to two weeks between meetings
- create a relaxed and informal atmosphere for the feedback meeting to enable patients to feel comfortable in discussing issues with clinicians

Reference

www.cgsupport.nhs.uk/Patient_Experience

5.3 Patient shadowing

Description

Patient shadowing is where a patient, member of staff or volunteer accompanies the patient on their journey through the health system. It is preferable that the 'shadower' does not have knowledge of the process and is comfortable asking the 'why' questions.

It provides objective, observational feedback that needs to be balanced by other approaches, for example by obtaining the views of the staff providing the service. The movement of the patient in time and space as well as perceptions of the service can be recorded. A comprehensive picture can be built up of movement combined with a flow diagram of actions and a qualitative perception of the process or whichever aspect is relevant to the improvement. While the patient is being shadowed, their 'shadower' can use interview techniques and observation to support the information provided by the patient. This approach is often combined with a patient diary.

When to use

- to map a patient process to find out what really happens on the patient's journey
- to monitor and measure service performance
- to identify training needs. It can also be used as a training and development tool to help staff understand what is important to patients

Advice

- establish what you are trying to achieve and how shadowing will help to reach your goal
- ensure the shadower fully understands and is comfortable with their role
- provide support for the patient and shadower and respect the contribution of time and effort from both
- feed back to the patient and the shadower how their work has helped with service improvement
- practice will increase the creativity with which patient shadowing can be used

Reference

Thomas S (1966) On the Right Track, Health Service Journal 25 April 31

5.4 Patient diaries

Description

A patient diary is a patient's record of events throughout their healthcare experience. This can include events, timings and actions, together with comments about feelings relating to the experience. The diary can also include personal emotions about experiencing the disease as well as staff attitudes, the environment and critical incidents associated with their journey. Whether the diary focuses on the whole journey or only one section of it will depend on the objectives and expected outcomes of the project.

In some services, such as pain management, the diary is also used as a log of treatment changes which is completed by members of staff. In this case the treatment details are kept separate from the commentary provided by the patient.

The written diary is only one approach. There are plenty of opportunities for creativity, including video or still photography, drawing, collage, electronic note pads and audiotapes.

When to use

- to analyse the detail of the patients' view of a service
- to identify issues that the patient may not remember to talk about
- to assess the ease or difficulties surrounding self-treatment

Advice

- ensure that the diarist has a clear understanding of what is expected of them and how their contribution will help to implement improvement
- patients are more likely to keep the diary if they have selected their preferred medium
- electronic notepads can be alarmed to remind the patient to make their entry at specific times
- video and still cameras will record risk factors of which the patients are unaware
- respect the time and commitment given
- keep in regular face to face contact with the diarist to resolve any issues, see how they are coping and to give them support
- feed back to the patient how their involvement has helped with future plans for the service
- diaries are confidential and must be recognised as being the patient's property. Ways for patients to share content without breaching confidentiality need to be agreed, such as a resource for them to answer specific questions

5.5 Discovery interviews

Description

Discovery interviews are semi-structured interviews with patients and their carers, usually undertaken separately. They use a framework based on the key stages of their journey through their experience of their illness. The framework, or 'spine', is designed specifically for the illness or condition of the patient group involved. The interviews are recorded and usually take place in the patient's own home.

Using the spine, the interview encourages patients to tell the story of their progression through their illness. This triggers memories and thoughts that will help to identify their underlying needs. It provides a very rich and powerful insight into the real experiences of the people involved. The focus of the dialogue is on the impact of the illness on their lives, rather than judgements about the services that they have received.

Feeding back the stories to local teams enables them to use their own knowledge and experience to identify needs and plan improved ways to meet them. The process is very much viewed as one of joint discovery, which is why the interviews are referred to as 'discovery interviews'.

When to use

- to learn directly from patients about their important needs
- to stimulate improvement ideas that can be tested out in practice.

Advice:

- keep the number of interviews manageable – experience shows many improvement ideas can come from a few discovery interviews
- gain each patient's consent and guarantee confidentiality and anonymity
- make sure all the improvement team are involved from the beginning
- plan carefully using the Toolkit, and ensure interviewers are trained
- gain ethical approval before beginning

Reference:

More information:

- there is an example of a discovery interview in the 'Improvement Leaders' Guide: Working in systems section 2.5
www.modern.nhs.uk/improvementguides
- for guidelines for undertaking discovery interviews go to www.modern.nhs.uk/chd and look for 'learning from patient and carer experiences' and discovery interviews.

5.6 Improving Practice Questionnaire (IPQ) and Critical Friends Groups (CFGs)

Description

The IPQ is an on-site survey administered by reception staff. There is a version of the questionnaire for GPs and nurses. It fits neatly onto both sides of one sheet of A4 paper. The results are fed back to individual GPs and nurses as well as the practice as a whole.

The individual GP and nurse results are based on communication skills and include benchmark scores as well as written comments from patients. These are provided to the GPs and nurses in a private and confidential manner. How they act on the results depends on whether they perceive a need to improve their communication skills.

The practice combines all the patient questionnaires without identifying individual GPs and nurses. They include not only communication skills but also issues such as access, availability, information-giving, reception staff manner and other practice issues.



Once the GP practice has received its results, the practice staff are encouraged to invite a small group of three to five patients to come to the practice and talk about the results together. This meeting of practice staff, usually a GP, nurse, practice manager and receptionist, and patients is called a Critical Friends Group (CFG) meeting. It is at this meeting that areas in need of improvement are identified and prioritised, and solutions are planned.

When to use it

- the Improving Practice Questionnaire (IPQ) is a useful tool to assist GP practices as part of their future GP contracts. It is used after the patient has seen the GP or nurse
- Critical Friends Groups (CFGs) are best used when there is an open culture in the practice and staff want to learn with patients about how to improve quality from a patient's perspective

References:

- Greco, M. and Carter, M. (2002) Improving Practice Questionnaire (IPQ) Tool Kit. Aeneas Press: Chichester, UK.

It may help to know from a patient and a member of the Collaborative that you are absolutely on course. I would like a health service that continues to inform and consults with me as a patient. That concerns itself with the prevention as well as the treatment of disease. That sees itself as one of the leaders of its local healthy community. That concerns itself with continually improving standards not just targets.

Patient attending Coronary Heart Disease workshop

6. Frequently asked questions

Question

How can we engage patients from different ethnic and socio-economic backgrounds?

Answer

Make use of contacts within their communities, such as healthcare workers, and especially link workers who are trained to communicate as well as being part of the community. Be prepared to go out to meet them, rather than expecting them to come to you: hold meetings or workshops in community centres, or ask for a slot on the agenda of one of the community's own meetings. Be sensitive to cultural and religious issues. Cultural calendars will clarify when the major festivals of your target population are held. Advertise in places where people go on a regular basis, such as shops. Make sure the potential benefits of involvement are clear, and offer to cover people's costs.

Question

How can we avoid tokenism and ensure that any views will result in meaningful changes and service improvement?

Answer

Be clear about the remit of the group and the role and responsibilities of the people you are working with. Are the people who will have to make any changes involved? Do you have the power to make decisions? If not, who does? Is the work closely connected to Trust priorities?

Question

What are some basic ground rules for involvement?

Answer

Think about how you would like to be treated in a social situation. For example:

- made to feel welcome and positively approached
- treated with the same respect as everyone else involved
- given information in advance and the need for your involvement made clear
- recognition of your personal situation for timing, transport, and special needs

Question

How does patient involvement fit with clinical governance?

Answer

Patient involvement lies at the heart of clinical governance and should be an everyday part of clinical governance activity. Clinical governance reports should clearly describe how continuous and effective patient involvement is being developed by care teams and how care has been improved as a result.

Question

Do we need ethical approval to get patients' views?

Answer

It is very important that patient involvement is implemented well and that patients' well being and dignity are defended. It is probably best to seek the advice of your Local Research Ethics Committee (LREC). They will be able to help you draw up a checklist of good practice and offer guidelines for determining when LREC approval will be necessary. There is more about ethics in the Improvement Leaders Guide: Evaluating improvement
www.modern.nhs.uk/improvementguides

Question

How do we decide who to involve?

Answer

First be sure of what you are trying to accomplish. Patients should be involved at this stage as well – they will be able to offer advice about who can help and how. Patient groups will be very helpful, but do not forget patients who are not represented by a group. A number of the stories in this guide describe how staff made efforts to contact patients individually.

Question

I want to organise and lead a patient and carer workshop. What advice can you give me?

Answer

Facilitating workshops is an important part of the improvement process and they are a useful way of gaining feedback from patients and carers as well as an opportunity to share information. Patients and carers can help with the design and delivery of the event. There are three areas to focus on: preparation, the event itself and the follow up.

Preparation

- discuss with patients and carers your ideas for the workshop
- set up a design team which includes patients, carers, sponsors and other stakeholders to plan and deliver the event
- define the purpose of the event in measurable outcomes
- identify a specific budget
- allow plenty of time to plan the event. Allow between four and six months for a national event
- define the delegates or audience to be invited. Identify the particular needs of delegates but assume that you will need a hearing loop and wheelchair access
- find a venue which is accessible to all participants and define specifications then check, recheck and recheck again
- make sure people have enough information in advance of the event to be able to contribute fully on the day
- when invitations are sent out ensure there is a contact person for people to ring to book transport and answer their queries
- define and refine language e.g. acronyms, abbreviations, NHS jargon etc.
- recognise that method and timing of follow-up needs to be included in the plan
- define venue and equipment specifications then check and recheck
- develop the programme in minute detail

The event

- check the venue the night before and confirm layout and positioning of tables, AV equipment etc.
- have hosts for every table who can welcome delegates, be available to answer queries and act as advocates as necessary
- make sure that people are really clear about the purpose of the day and their role in it: patients, carers and staff etc.
- agree ground rules and agenda with the delegates
- any keynote presentation needs to be inspirational, really relevant and short
- create contact postcards for the event with consent paragraph to develop database of contacts for further involvement
- the sponsor or key player needs to be present but don't assume that they have to take a lead in the event
- ensure that the programme is achievable and flexible and includes time for discussion and group activities
- provide frequent breaks and refreshments including lunch with seating
- explain clearly how and when you will be feeding back to delegates
- have someone available at reception all day for queries and organising expenses

3. Follow-up

- hold an immediate debrief with all members of the event team including the hosts, focusing on the positive and take notes
- analyse evaluation and type up outputs from the day
- write and thank all contributors
- follow up on any photography or video recording of event
- allow at least two weeks for initial follow-up
- feed back outcomes from the event to all participants by the agreed date
- if there is a delay in the process then let people know about it and why
- keep the contact number live so that queries can still be answered easily
- once all follow-up tasks are completed meet again to look at lessons learned and opportunities for improvement
- create an archive file on the event

You will find a lot more useful advice in the Improvement Leaders' Guide: Working with groups www.modern.nhs.uk/improvementguides

Question

Where can I get more information about how to involve patients, carers and the public

Answer

You will find a lot more information in the Patient Experience section on the Clinical Governance Support Team web site www.cgsupport.nhs.uk/Patient_Experience. Also use the internet, it really is a great source of information.

Question

How can I raise the profile of patient and carer needs in our local training programmes

Answer

Look at the following case study as a way to do it. It's all about involving patients and carers with staff and learning about improvement together. The Improvement Leader said "We have learned to move at the pace the organisation can accommodate and by linking to existing strands of work we have prevented the feeling of this being another initiative".

Case study

Learning from patient and carer stories in the Northwest: an award winning initiative

Our new learning policy and strategy makes a radical commitment to patient centred learning. Prior to this, the traditional approach to learning events had been driven solely by the needs of the staff and had not included the needs of our customers: the patients and their carers. So we engaged experimentally with patients as partners and our early experiences demonstrates the benefits of making a greater investment in this partnership approach to learning.

Specifically we have designed and facilitated learning opportunities for both professional and support staff to include a patient focus, using a collection of local patient experience stories in a variety of media.

It might be expected that all staff within a caring 'industry' such as health would as second nature put the patient first in all their activities. We know this is why most staff entered the service. However we wanted to:

- provide a safe learning environment for staff to reflect on practice and positively accept and act upon comments received now that patients are becoming more demanding and articulate
- re-awaken the empathy staff have with patients and to remind them that they are caring for vulnerable individuals in settings unfamiliar to them
- have patient perceptions of the services help us question the way in which we deliver and improve them

Our initial approaches have been through newly designed development programmes for ward managers. Since then we have introduced the approach to a number of existing programmes for clinical support workers, newly qualified nursing staff beginning their careers in the organisation, and a programme for Physiotherapists, Biomedical Scientists and other Allied Health Professionals.

Continued on next page

60 ward managers have participated in management development programmes that used materials from the story bank, producing patient focused improvements to their services. A further 40 nurses and allied health professionals are embarking on this learning venture now. More than one hundred clinical support workers have discussed the messages within the videos and an NVQ in Care programme has brought this way of examining practice to another 50 workers. Some programmes have been developed for clinical teams involving 120 people of different professional backgrounds working and learning together.

Examples of their improvement work include:

- reviewing information available to patients
- considering the privacy and confidentiality issues on wards
- changing toileting procedures in clinical areas
- addressing pre surgical control of infection measures
- ensuring better explanations about location of food and drink on patient tables for visually impaired patients
- elderly patients being discharged with packed meals when leaving hospital in the evening
- a TOP TIPS leaflet to help patients when they first attend the out patient department
- reviewing the layout of the equipment in the Endoscopy department as well as written confirmation of results when patients leave

A second strand of work has been the way in which we are using patient story material with cross sections of staff including medical staff.

We have been active in keeping the Trust Board informed of progress, working most closely with the Nursing Director, and are also linking to the very important agendas of clinical governance and improved basic nursing care.

Through patient feedback, we can measure the changes and we can feel a real difference in the attitudes of those who have started looking through the eyes of the users. We have learned that by allowing our staff the time to reflect on some 'live' stories from our own patch we can re-motivate them and see them taking ownership of improving their services.

The Improvement Leaders' Guides have been organised into three groups:

General improvement skills
Process and systems thinking
Personal and organisational development

Each group of guides will give you a range of ideas, tools and techniques for you to choose according to what is best for you, your patients and your organisation. However, they have been designed to be complementary and will be most effective if used collectively, giving you a set of principles for creating the best conditions for improvement in health and social care.

The development of this guide for Improvement Leaders has been a truly collaborative process. We would like to thank everyone who has contributed by sharing their experiences, knowledge and case studies.

Design Team

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To download the PDFs of the guides go to www.modern.nhs.uk/improvementguides

We have taken all reasonable steps to identify the source of information and ideas. If you feel that anything is wrong or would like to make comments please contact us at improvementleadersguides@modern.nhs.uk