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Acknowledgements

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Improvement Leaders' Guide to Involving patients and carers



I am pleased to present this guide – another in our series for Improvement Leaders in the NHS.

Earlier this year we launched the first three guides in this series and it is great to report how well they have been received by staff from all parts of the NHS and with other partners in healthcare.

In the NHS Modernisation Agency we try to follow five simple rules. These are to:

- see things through the patients' eyes
- find a better way of doing things
- look at the whole picture
- give front line staff the time and the tools to settle the problems
- take small steps as well as big leaps.

All Improvement Leaders' Guides are underpinned by these rules, as we feel that these are the things that are truly going to make improvements for our patients.

The first guides on Process Mapping, Analysis and Redesign, Matching Capacity and Demand and Measurement for Improvement gave real, practical advice about the basics of improvement. These next four guides tackle some of the softer issues about people:

- Managing the human dimensions of change
- Involving patients and carers
- Sustainability and spread.
- Setting up a collaborative programme

It is only by testing ideas, learning what works best and sharing our knowledge that we will really make things better for our patients. The content of these guides will be updated over time, so if you've found this printed version useful, keep checking the website, www.modern.nhs.uk/improvementguides It is here that the guides will be regularly updated as we learn more and have new things to share. There will also be news of more Improvement Leaders' Guides coming in the autumn. These include the topics of working across organisations, leadership in improvement and designing new roles in healthcare.

Remember that the guides are meant for Improvement Leaders at every level in healthcare, on the frontline just as much as in the boardroom. We need Improvement Leaders with passion, integrity and energy who can breathe life into the simple rules listed above and make them work on their patch for their patients. In many places such local leaders are already achieving tremendous results and the guides are here as an extra source of support for everyone in healthcare.

David Fillingham
Director, NHS Modernisation Agency

Foreword



The Improvement Leaders' Guides

Collectively the Improvement Leaders' Guides form a set of principles for creating the best conditions for improvement in healthcare. The greatest benefit is when they are used to support a programme of training in improvement techniques.

Where should I start?

The seven guides are not sequential and ideally you should read them all at an early stage in your improvement project, to be aware of the tools and techniques in all the guides. However there are some things we would suggest you should do first, as you develop your plan based on local needs and experience.

Each guide includes

- some background information on the topic
- some activities which you, as an Improvement Leader, may find useful to help the teams you work with understand the basic principles
- questions that are frequently asked about the topic and suggested ways to answer them
- guidance on where to go for more information. Sources include the excellent toolkits that have been produced to support improvement programmes in specific services, such as Cancer, Critical Care, Mental Health and Clinical Governance. Useful books, papers and websites are also listed

What's in each guide?

Improvement Leaders' Guide to...

What the guide has to offer an Improvement Leader

<p>Process mapping, analysis and redesign www.modern.nhs.uk/improvementguides/process</p>	<p>This is definitely the place to start. This guide offers help in the use of the 'Model for Improvement'. This is a framework for setting aims, identifying the possible changes and beginning to think about measures that will show that your changes have made an improvement. Then there is the vital first stage of mapping your chosen patient process and analysing it to really understand what is happening.</p>
<p>Measurement for improvement www.modern.nhs.uk/improvementguides/measurement</p>	<p>Question: how do we know a change is an improvement? Answer: by measuring the impact of the changes. This guide should also be considered very early on in an improvement project and gives valuable advice on what and how to measure for improvement and how to present the data to interested parties.</p>
<p>Matching capacity and demand www.modern.nhs.uk/improvementguides/capacity</p>	<p>In our experience the process of truly matching capacity and demand has led to some of the most exciting changes in a healthcare process. This guide explains the most effective ways to understand the capacity and demand of a service and the 'bottlenecks' in the system which often cause patients to wait. It goes on to suggest ideas to reduce or eliminate these queues and waiting lists for patients. It is vital that process mapping and analysis is done prior to using this guide.</p>
<p>Involving patients and carers www.modern.nhs.uk/improvementguides/patients</p>	<p>Everything we do should be focused on patients and their carers. They must be involved in our improvement programmes and projects from the very beginning. We are able to offer advice based on current thinking and experience of how to involve patients and carers in the most effective way, with warnings of possible pitfalls.</p>
<p>Managing the human dimensions of change www.modern.nhs.uk/improvementguides/human</p>	<p>Some of us take to the idea of change more easily than others. Some like to develop ideas through activities and discussions, while others prefer to have time to think by themselves. We are all different and need to be valued for our differences. This guide gives ideas of how to ensure the best possible outcome when working with different people.</p>
<p>Sustainability and spread www.modern.nhs.uk/improvementguides/sustainability</p>	<p>It is fundamentally important that after making improvements they are sustained and built upon. This is a real challenge to anyone involved in improvement projects. It is also important that we share our learning and ideas with other areas of healthcare so that the maximum number of patients can benefit. This guide suggests methods and principles based on experience from healthcare both in England and beyond for sustaining and spreading improvement ideas.</p>
<p>Setting up a collaborative programme www.modern.nhs.uk/improvementguides/collaborative</p>	<p>Experience has shown that working collaboratively produces the best environment for creating and sharing improvement ideas. Use this guide when a group of healthcare staff want to work in a different way, to innovate and test new models of delivering care, to dramatically improve the service for a group of patients and to create learning for their own organisation and the whole of the NHS.</p>

A few additional thoughts about the guides

The guides are based on current thinking and experience.

Be aware that this is constantly changing. Check updates on the Improvement Leaders' Guides website, www.modern.nhs.uk/improvementguides, which will be updated often as we test out and learn from new techniques.

Be aware of your own experience.

If this field is totally new to you, plan how you can find out more through further reading or development courses. If you are more familiar with leading service improvements, can you share your experiences and knowledge with others in your healthcare community and the wider NHS?

Make contact with others who have improvement skills.

Many people in healthcare have had training in the improvement skills contained in these guides. Their training will most likely have been for a particular service such as primary care, dermatology or cancer. Make contact with them to form a health community improvement network to support and learn from each other.

Try it for yourself.

These guides don't represent the only way to do things, but they provide a good starting point. Create your own case studies and then share your experiences.

Take the thinking forward.

The website will be a dynamic medium. Please contribute to the discussion if you can. We would welcome and value your experience.

Have fun.

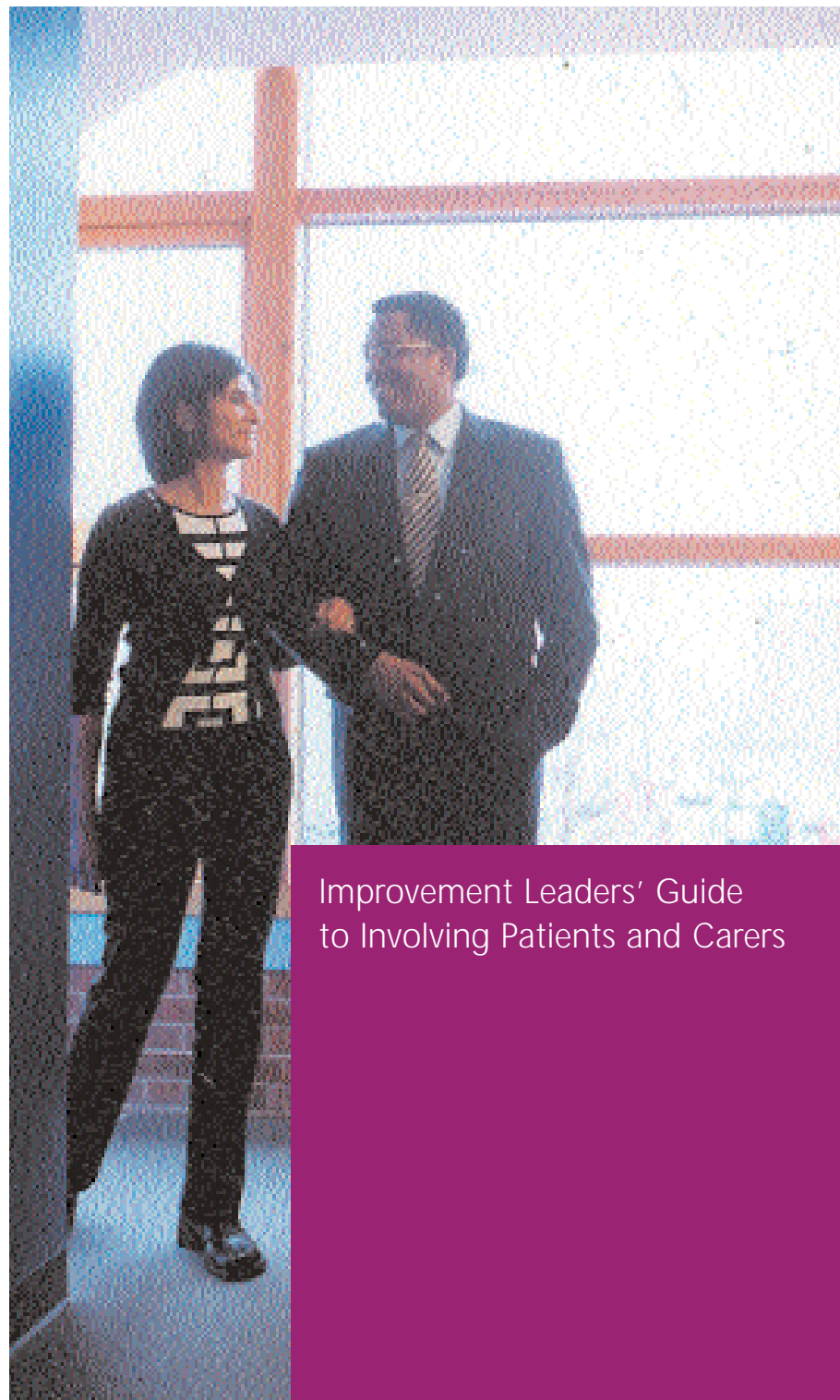
Many have said that leading an improvement project has been one of the most enjoyable and fulfilling roles of their careers!

Let us know what you think of the guides.

We want your comments and thoughts about the Improvement Leaders' Guides. Our aim is to keep improving them so let us know what you think:

- how can we improve the guides? Is there anything we have left out?
- have you found them useful? If so which guide in particular and which section?
- how have you used them? Can you tell us any stories?
- if there were to be other guides, what topics should they be on?
- have you visited the web site? How can we improve it?
- is there any thing else you would like to tell us about the Improvement Leaders' Guides?

Email us now at improvementguides@npat.nhs.uk



Improvement Leaders' Guide
to Involving Patients and Carers

“ 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 and public involvement
2. Involving patients in every aspect of improving services
3. Some stories of involvement
4. Helping to strengthen patient involvement within organisations
5. Some approaches that have been used to involve patients in improving care:
 - critical incident technique
 - focus groups
 - patient shadowing
 - patient diaries
 - discovery interviews
 - improving practice questionnaire and critical friends groups
6. Frequently asked questions and answers
7. Useful reading and contacts

A note about terminology

There are a number of different terms in general use to describe people who use health and community care services. For the purposes of consistency, and to reduce confusion, this guide uses the term ‘patient’ throughout to cover patients, users, carers and clients. 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 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 should also be useful to all those who will actually be involved in the process. It aims to help to realise the underpinning goal of truly integrating all those involved in the NHS, whether providers or receivers of care.

More specifically the guide’s purpose is 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
- provide signposts to further reading, hyperlinks and others undertaking similar work

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 experience 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 NHS, 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.

A later section briefly describes some different approaches to involvement and partnership that can be used to learn about patients’ experiences as they move through the NHS system of care. For those of you wanting to think about how to sustain and strengthen patient involvement across their organisations, there is a short list of key questions that need to be addressed by senior managers and planners.

The guide is neither a textbook nor a cookbook, nor can it possibly be comprehensive. It links closely with other Improvement Leaders’ Guides, as on [see www.modern.nhs.uk/improvementguides](http://www.modern.nhs.uk/improvementguides)

As mentioned earlier, the NHS Modernisation Agency is very aware of the rapidly growing body of experience across the NHS. The intention is to annually update all the guides to reflect growing experience; and one way to let others know about your own experience and learning will be by using the website.

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 redesign 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. Introduction to patient involvement

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. Guidelines for undertaking activity at these levels are being developed collaboratively by the Department of Health, the Modernisation Agency and other organisations such as the Commission for Health Improvement. They 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 Processes
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 is seen as having 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”. Responsibility for supporting this has been given to the Modernisation Agency, which has been asked to “advise the NHS on how to achieve the widest possible involvement of patients and the public in the NHS at a local level” as required by the Kennedy Report. For more information about the Kennedy Report look in the publication section at www.doh.gov.uk

The need to involve patients has been reflected in a wide range of government publications during the past several years, and by a rapidly increasing growth and diversity of patient involvement activities across the NHS. In addition, the Department of Health is actively considering strategies that amongst other things will strengthen communication between patients, staff and NHS organisations.

A number of new bodies have been created which together will provide a

comprehensive network to support patient and public involvement at national and local levels. These include the National Commission for Patient and Public Involvement in Health (CPPIH), the local Independent Complaints and Advocacy Services (ICAS) and Patients’ Forums and the Patient Advice and Liaison Services within Trusts (PALS).

It is important to emphasise that involvement is not just for closer scrutiny of services. 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.

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.

As mentioned above, the emphasis is very much on creating genuine, ongoing partnerships where all the people involved, patients and staff, are acknowledged as having a particular and unique contribution and are respected as equals. We need to

Expert Advisor Model versus Partnership Model

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

embrace methods that will advance this. There is a growing shift beyond traditional approaches, where involvement often meant consultation that ceased 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 table above.

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 on the following page. 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 King’s 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*
 For more information contact the College of Health www.collegeofhealth.org.uk

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"

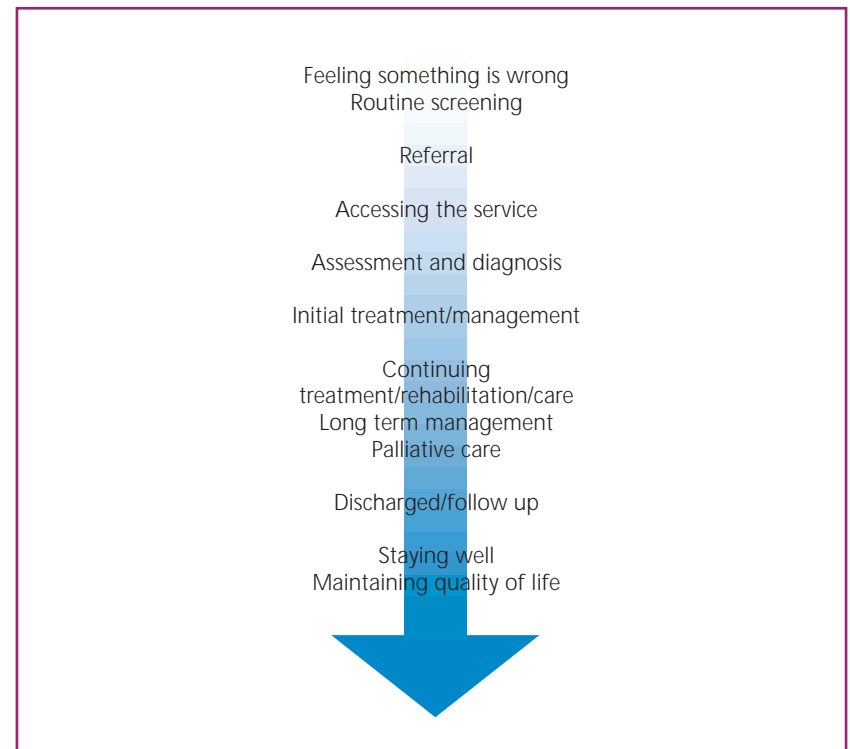
Voices in Action

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. This should include 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 following diagram 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.

A patient's possible journey through care

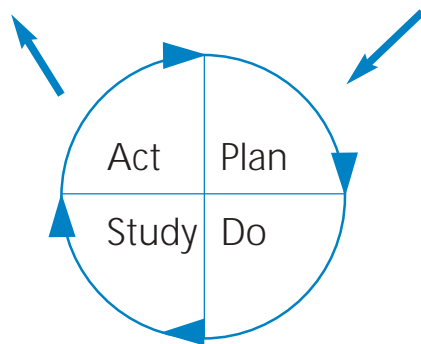


Agreed courses of action may be undertaken by patients themselves, by staff team members or jointly by both, reinforcing the point that ideally everybody should be considered to be members of the same team. Any form of involvement must lead to demonstrable benefits to patients. The Improvement Leaders' Guide to Process Mapping and Analysis www.modern.nhs.uk/improvementguides/process

describes how teams working together can redesign the processes underpinning their practice 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.

The Model for Improvement (© IHI)

Model for Improvement
What are we trying to accomplish?
How will we know that a change is an improvement?
What changes can we make that result in improvement?



The Model for Improvement
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

2. Involving patients in every aspect of improving services

Involving patients in every aspect of improving services 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.

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.

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.

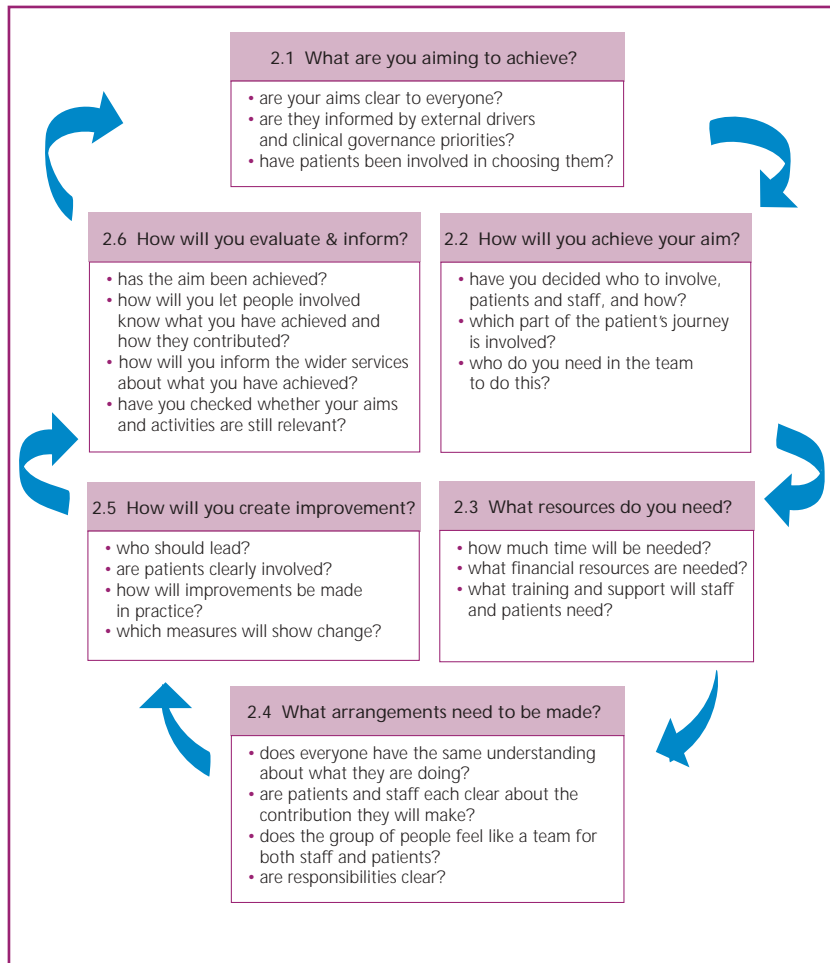
2.1 What are you trying to achieve?

When deciding where to begin it is important both to take account of drivers from outside the organisation and to use knowledge from within. For example, external drivers may include priorities from Health Improvement Programmes or Health Action Zones. 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

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 staff, senior managers and clinicians must all be included and must feel that what they are tackling is

Involving patients at every stage



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 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 in principle, and will help 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 to Managing the Human Dimensions of Change, www.modern.nhs.uk/improvementguides/human

Senior managers and clinicians

Managers and clinicians may be involved in their own right and will have the additional role of identifying resources and providing support for the changes that will emerge. If they have not already been involved in agreeing the priorities, the chief executive and appropriate board members of the Trust must be informed of the activity and its aims.

2.3 What resources do you need?

Three things will need important consideration: time, finance, and training 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 time is a precious commodity. 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. Consider expenses as these can be significant. Not only expenses for travel and cover for care but also for sundries such as stationery. Each situation will have its own particular needs.

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.

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.

The Four Rs of working together

Remit

- 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? If not, people may be 'travelling' in different directions and working at cross-purposes.

Role
Relationships
Responsibilities

- is each member clear about his/her particular role?
 - what contribution does each person think they are able to offer?
 - what do other people think your role is?
- 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. Does that mean that he/she is a representative of that organisation, or that the GP is representative of all the GPs in the PCT? Or are they each just bringing their individual and unique patient or health professional perspective to the discussions? It is important to check it out so that everyone is clear.
- 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?
- 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 to Managing the Human Dimensions of Change, www.modern.nhs.uk/improvementguides/human
- what is the group responsible for and to whom? (see terms of reference above)
 - 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?
- 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?

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 an existing group of patients 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 on the previous page. This will enable the multidisciplinary group members 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' Guide to Process Mapping, Analysis and Redesign, www.modern.nhs.uk/improvementguides/process, and the Improvement Leaders' Guide to Matching Capacity and Demand, www.modern.nhs.uk/improvementguides/capacity, provide clear guidelines for establishing improvement initiatives.

Patients should continue to be involved as team members throughout all stages of any improvement 'project' process. It is probably more helpful to think of continuous patient involvement and continuous improvement as being synonymous. 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. You will find more information in the Improvement Leaders' Guide to Sustainability and Spread at www.modern.nhs.uk/improvementguides/sustainability

Building in simple measures is crucial to success. Ways to do this are described in the Improvement Leaders' Guide to Measurement for Improvement, www.modern.nhs.uk/improvementguides/measurement. 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 – and in such ways that patient involvement is also seen as part of that everyday practice.

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.

3. Stories of involvement

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 two hundred and fifty 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-centered improvements.

What was done?

The Improving Practice Questionnaire (IPQ), a one-page survey, was given to patients on-site after they had seen the doctor or nurse (see section 5.6). It has been validated extensively and 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 below.

3.1.1 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-centered and patients can help in finding practical solutions
- dialogue between staff and patients is at the heart of partnership

3.1.2 Focusing on one GP's consultations

The IPQ contains a section on the patient's experience of the consultation. Confidential feedback can be provided to an individual GP or nurse about his/her 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 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 patient 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 health care 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 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. Two of them give brief accounts of their role on the following pages.

Thoughts from a service user champion

I am the service user champion at the Local Modernisation Review Group. My role is, I believe, a first in the country, and involves championing the cause of user requirements within the group, and actively liaising between service users, the carer champion, the group, 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.

The Model for Improvement has been used to design and evaluate the change efforts made. 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.

Thoughts from a carers' champion

I joined the group as carers' champion on 5 October 2001. 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, action (PDSA) cycle is our selected tool to achieve modernisation.
- 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 action 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 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

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

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. The Cancer Collaborative Services (CSC) programme manager was also involved. For more information about CSC see the

Improvement Leaders' Guides to Setting up a Collaborative Programme, www.modern.nhs.uk/improvementguides/collaborative

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 group to discuss the topics that had arisen. The CSC programme manager facilitated the discussion. 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 CSC Programme Manager and 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 patient as '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. Two hundred and fifty 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 5.2) 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 professionals 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 professionals 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 by patients
- 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 receive systematic and formalised support from a range of professionals throughout their

journey. Patient surveys and studies indicated a high level of satisfaction, but as part of the Orthopaedic Services Collaborative it was thought that there was 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 more 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 in putting together service improvement plans
- 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 within the Coronary Heart Disease Collaborative 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 it did lack the 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. A toolkit has been developed to guide the process.

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

A Changing Workforce Programme (CWP) pilot programme in diabetes care was set up across two towns. The aim of the CWP is to test and implement new ways of working to improve the service and to increase job satisfaction for staff. These are

two 'typical' towns in England, with 'typical' health services, but they have 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 health care 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. The results will be formally analysed once all the returns are in
- **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 that staff have
- remember that patients/carers are people, who have interests, skills and expertise to contribute beyond their experience of being a patient/carer
- don't forget the counter-balance of the staff perspective: all of the above exercises have involved both patients and staff

For more information look at Changing Workforce Programme on the NHS Modernisation Agency website, www.modern.nhs.uk

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 on the Clinical Governance Development programme: 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 who 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 suggesting that 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 design and create simple, inexpensive solutions that meet their needs better.

4. Helping to strengthen patient involvement within organisations

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 strategic and business plans 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. Some approaches that have been used to involve patients in improving care

5.1 The Critical Incident Technique

Description:

The Critical Incident Technique is a fairly unstructured way of listening to the patient experience, allowing the interviewee flexibility to talk about their views.

An interviewer describes the scope of the improvement project by outlining the area they would like to cover in the session. They then listen to the patient's experiences, identifying any critical incidents. A critical incident is described as:

- an action or inaction that causes an opinion to be formed
- an environmental or other factor that causes an opinion to be formed

If an incident does not trigger a value judgement then it is not deemed 'critical'. The critical incidents, once identified, are compared with those from other interviews. Frequently mentioned incidents or themes can be used as the basis for further enquiry or the initiation of PDSA cycles. It is surprising that a very small number of interviews need to be performed before common themes appear.

It is useful to record the session, with the patient's permission, in order to make an accurate transcription of the interview. A typical interview lasts about one hour.

When to use it:

- to identify where patients and carers perceive the problems to be
- to find out how common a problem might be
- as an introduction to involving patients in projects when the project team have little experience of this type of involvement

Simple advice:

- if you are not experienced in this method, practice with colleagues before visiting patients
- it is important to put arrangements in place for debriefing both the interviewer and interviewee if necessary

Reference:

www.aorn.org/journal/2001/octrc.htm

5.2 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, health care 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 to 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 it:

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

Simple 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

5.3 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 it:

- to map a patient process to find out what really happens on the patients' 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

Simple 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 1996 25 April 31

5.4 Patient diaries

Description:

A patient diary is a patient's record of events throughout their health care 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 it:

- 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

Simple 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

Reference:

- www.chi.nhs.uk/eng/cgr/acute/pd_access_to_care.pdf

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. A toolkit containing guidelines for undertaking discovery interviews is available on the Modernisation Agency website.

Using the spine, the interview encourages patients to tell the story of their progression through their illness. This triggers significant 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 value judgements about the services that they have received, although they weave accounts of their care into their stories.

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 them:

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

Simple 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:

- go to the NHS Modernisation Agency website on www.modern.nhs.uk/serviceimprovement and look at Coronary Heart Disease, Collaborative Toolkit: Learning from Patient and Carer Experiences

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) as well as 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 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 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:

- <http://latis.ex.ac.uk/cfep>
- Greco, M. and Carter, M. 2002. Improving Practice Questionnaire (IPO) Tool Kit. Aeneas Press: Chichester, UK.

6. Frequently asked questions and answers

Question

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

Answer

Make use of contacts within their communities, such as health care workers, 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?

Answer

It is very important that patient involvement is implemented well and that patients' well being and dignity are defended. There is currently considerable debate about the best way to achieve this and it will probably be some time before things are resolved. In the meantime it is probably best to seek the advice of your Local Research Ethics Committee (LREC). They may be able to help you draw up a checklist of good practice and offer guidelines for determining when LREC approval will be necessary.

- The College of Health: Voices in Action Resource Book and Consumer Action Guidelines – www.collegeofhealth.org.uk
- Making Radiology Services more Friendly – www.rcr.ac.uk
- Database of individual patient experiences (DIPEX) – www.dipex.org
- Signposts – a practical guide to public and patient involvement in Wales – www.cymru.gov.uk/signposts
- National Consumer Council – www.ncc.org.uk
- NHS Modernisation Agency – www.modern.nhs.uk
- NHS Modernisation Agency Clinical Governance Support Team – www.cgsupport.org

But also look in the reading section of the Improvement Leaders' Guides where there are more books and articles – www.modern.nhs.uk/improvementguides/reading

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 have found the stories in section 3 really interesting and useful. Where can I find more information about these case studies?

Answer

For more information and contact details, look at 'Involving Patients and Carers Stories' in the useful reading section – www.modern.nhs.uk/improvementguides/reading

Question

Where can I get more information about these techniques?

Answer

These websites offer useful help about involving patients and carers.

7 Useful reading and more information

Much has been written about improvement and change. So much, that it is very easy to get overwhelmed by all the material. So we've gathered together the things that we think you might find most useful. We would like to guide you in three directions:

1. Toolkits

These have been developed by national and regional programmes for staff addressing the issues for one particular aspect of care. This can range from general workforce planning issues to addressing the problems of a particular service, e.g. mental health, endoscopy or orthopaedics. They are written for clinical staff in the specific service and will give you many more change ideas, lots of case studies, national contact names and information on how to access up-to-date improvement activity in that particular area or service.

Use: when you have identified a problem associated with a particular service.

2. Books, papers and articles

These have been written by international experts in their field addressing the science and theory behind many of the tried and tested tools and techniques in the guides.

Use: when you want a deeper understanding in any of the topics.

3. Websites

Time is precious and the World Wide Web is vast. Therefore, we want to guide you to the selected web sites designed to extend your knowledge and thinking on improvement theory.

Use: when you want to extend your general knowledge and gain access to improvement thinking around the world.

So visit the Improvement Leaders' Guide web site for the useful reading section at www.modern.nhs.uk/improvementguides/reading This will be continuously updated as new editions are published and you tell us what you find useful.