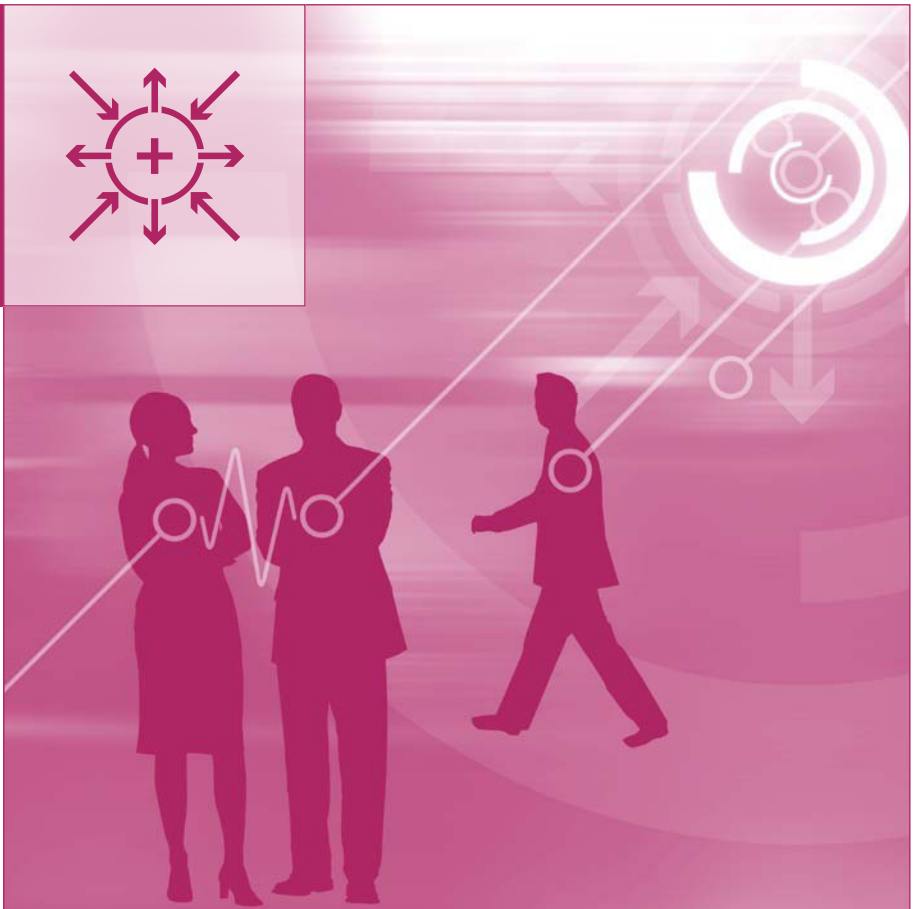


Improvement Leaders' Guide  
Involving patients and carers  
**General improvement skills**



# Improvement Leaders' Guides

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

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

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

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

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

- Working in systems
- Redesigning roles
- Improving flow

You will find all these Improvement Leaders' Guides at [www.institute.nhs.uk/improvementguides](http://www.institute.nhs.uk/improvementguides)

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

Discipline of Improvement in Health and Social Care

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

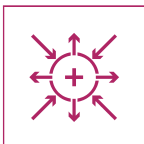
Patient





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# 1. Introduction to patient involvement

## A note about terminology

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

## About this Improvement Leaders' Guide

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

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

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

## Touchstones for involvement as a continuous and effective process:

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

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## 1.1 The bigger picture of patient involvement

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

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

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

| <b>Different elements of patient involvement</b> |                         |                     |                   |
|--|-------------------------|---------------------|-------------------|
|  | Strategic Policy Making | Service Development | Treatment Process |
| Informing  |                         |                     |                   |
| Consulting                                       |                         |                     |                   |
| Partnership                                      |                         |                     |                   |

## 1.2 Background and context

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

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

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

Potential benefits for patients and carers may include:

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

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

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

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

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

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

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



## 1.3 Involving patients in designing improvement

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

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

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

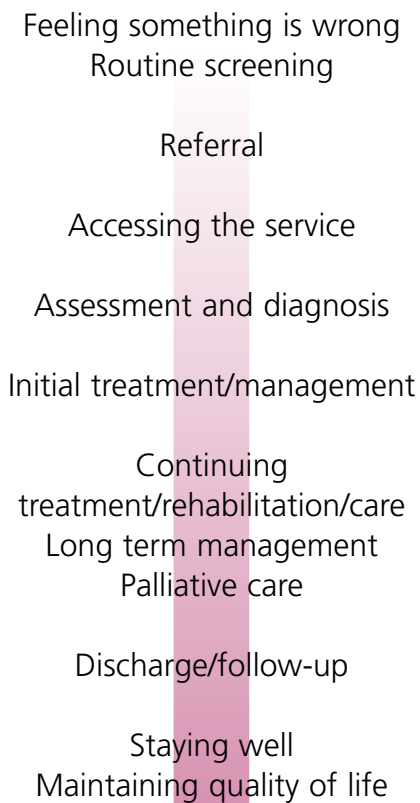
Voices in Action

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

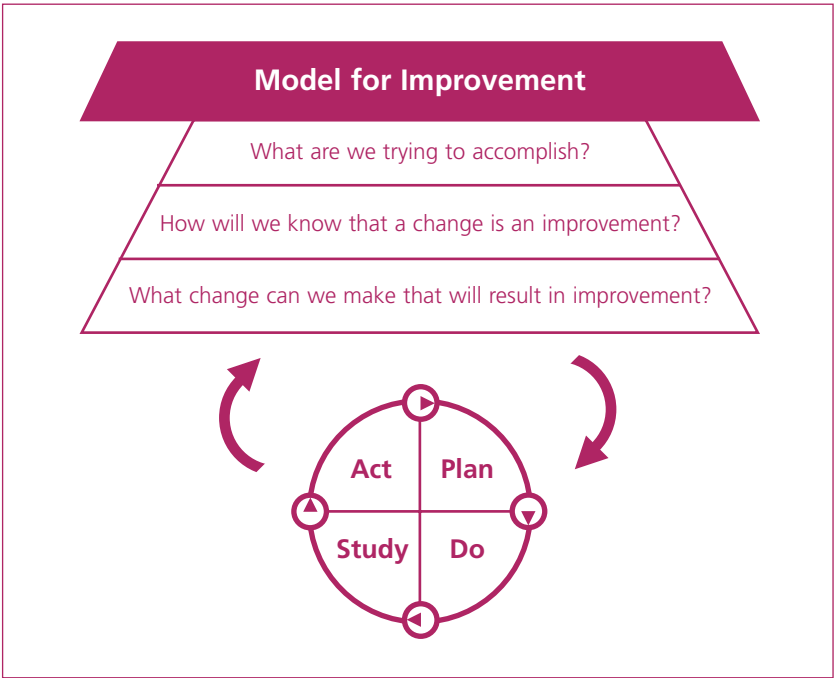
Patients should be involved at all stages of the improvement process, including discovering needs for improvement, designing improvements and learning from the outcomes of improvement efforts. Involvement is about truly creating working partnerships – not 'doing to' or even 'doing for' patients.

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

## A patient's possible journey through care



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



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

































































































