



# ENGAGING AND COMMUNICATING WITH PATIENTS, CARERS AND THE COMMUNITY: a guide



---

## Briefing summary

---

- **Who:** For people setting up or running health care improvement projects in the NHS.
- **Why:** Involving patients, carers and the community in improvement work can help you identify the right solutions and engage others.
- **What:** The briefing summarises the benefits of involving patients, carers and the community in your work, together with advice on how to do so.

---

## Why involve patients in improvement work?

---

*“Patients almost always have a different perspective on who is the most important person involved in their care, and on how the professionals treating them work together.”*

Professor Jane Maher, Chief Medical Officer, Macmillan Cancer Support

*“Nobody is more infectious and enthusiastic than patients in improving care. They are a natural inspirer.”*

Phil Stylianides, Director, Picker Institute Europe

Involving patients, carers and the community in improvement can be challenging, but if you involve them in the right way it can increase the impact of your work.

Their involvement can help you to:<sup>1</sup>

- ensure that any changes you make reflect their needs, experiences and priorities
- identify solutions that tap into the resource provided by patients and carers – for example, opportunities for them to self-manage their care, or solutions that help improve adherence to treatment plans
- keep your project team motivated
- inspire others to support the changes you want to implement.

---

<sup>1</sup> The Health Foundation. Involving Patients in Improving Safety: evidence scan, The Health Foundation, 2013.



## How to involve patients and carers in improvement work

The NHS Institute for Innovation and Improvement has recommended the following touchstones for patient involvement:

- 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.<sup>2</sup>

It is important to be clear from the outset about the roles patients, carers and the community might play in your improvement work.

The Picker Institute is a charity with a long track record of making patients' views count in health care. Phil Stylianides from Picker says: *“Before you begin, ask yourself: ‘Are you willing to be truly open and committed to involving patients or will you end up simply ticking a box?’ Even with good intentions, it is all too easy to find yourself working within fixed parameters that patients can’t meaningfully influence. Another common mistake is to involve patients only at the beginning of a project. For the benefits to be realised, it must be a continuing commitment.”*

It is also important to assess whether you have the skills, resources and capacity within your project team to listen to – and build good two-way relationships with – patients, carers and the communities you might need to involve at each stage of the process. This might include providing support and training, and will almost certainly involve some financial resource – for example, expenses for travel and refreshments.

Many NHS Trusts have patient involvement teams that should be able to provide advice and guidance on involving patients. So make use of their expertise.

<sup>2</sup> NHS Institute for Innovation and Improvement. Improvement Leaders' Guide to Involving Patients and Carers, NHS Institute for Innovation and Improvement, 2005.



---

## Methods of patient involvement

---

You can involve patients, carers and members of your community in your improvement work on any of four levels:

- 1 Enabling them to play a formal role on governance, steering or advisory groups.
- 2 Seeking their views on their experiences of their care, and on how care can be improved.
- 3 Involving them in the design of any change or intervention.
- 4 Helping you to win hearts and minds.

Some of the main approaches are summarised below.

### 1 Involving patients in steering your improvement work

Some improvement teams create formal roles for patients or patient representatives on project governance, steering or advisory groups. Success here can depend on:

- a) clearly defined roles, with a shared understanding of what's expected of lay representatives
- b) clarity about which aspects of the work they can influence
- c) the skills of the individuals involved, and their ability to influence and steer the management of a project appropriately.

Where health problems may prohibit individual patients from taking on extended commitments, representatives of patient organisations and charities can be better placed to champion their needs through a role on a committee or advisory group. Charities like Macmillan Cancer Support often use trained patient advocates to work alongside patients and help them express their stories, priorities and needs.

### 2 Listening to patients' views and experiences

To improve patient care, it is essential to understand patients' experiences of current care provision. Patients' views can be gathered through a range of methods, including: 1-1 interviews, surveys, focus groups, patient diaries, clinician-patient meetings, patient shadowing, listening events or even informal coffee mornings with members of a local patient support group.

Gaining a more representative picture is much easier to achieve when there is a defined cohort of patients – ie for a specific service. Phil advises that improvement leads, working on projects involving multiple services, should start by focusing on the needs of patients at a site/service level, and then take the learning out further to explore what the findings might mean for patients in other services.

You may also need to secure patients' written consent and/or seek ethical approval – for example, for their involvement in research. You can seek the advice of your Local Research Ethics Committee (LREC). They will be able to provide advice on good practice and help you determine when LREC approval will be necessary.



---

## ENGAGING AND COMMUNICATING WITH PATIENTS, CARERS AND THE COMMUNITY: a guide

---



### 3 Involving patients in work to co-design services

Co-design approaches encourage and empower patients to actively develop solutions that will improve patient care. They blur the distinction between the user of a service and the person designing or developing it. These approaches are founded on the belief that, by creating solutions together, service users and service designers will arrive at a better end result.

Professor Jane Maher from Macmillan Cancer Support Maher says: *“Co-design can help you really understand what happens to people throughout their treatment and what matters to them, but it also means giving up some control. If you’re going to use co-design methods, you may have to stand by the solutions that patients identify, even though those solutions may not be what you originally intended.”*

### 4 Involving patients in communicating your improvement work

If you have involved patients, carers and members of the community meaningfully as your work develops, you should find you have established a pool of potential advocates that you can call upon to influence others. Recipients of Health Foundation grants have testified how powerful these advocates can be, with some sharing patients’ stories to influence clinicians, and involving patients or carers as part of the team presenting at meetings – for example, to commissioners, executives, other patients or local politicians.

---

## What others say

---

*“The patient perspective is key. Their voice is a very effective communications tool.”*

Michael Nation, Development Director, Kidney Research UK

*“When involving patients, it’s the detail that counts. If you’re asking patients to speak up in meetings, you will need to provide them with appropriate training and support. If you’re asking them to travel to events, you will need to pay expenses up front. If you develop recommendations on the back of your work with patients, make sure you tell them what you have decided so that they have an opportunity to respond.”*

Professor Jane Maher, Chief Medical Officer, Macmillan Cancer Support



# ENGAGING AND COMMUNICATING WITH PATIENTS, CARERS AND THE COMMUNITY: a guide



---

## Resources

---

*Involving Patients in Improving Safety: evidence scan*, The Health Foundation, 2013.

[www.health.org.uk/publication/involving-patients-improving-safety](http://www.health.org.uk/publication/involving-patients-improving-safety)

Person-centred care resource centre, The Health Foundation.

<http://personcentredcare.health.org.uk/>

*Improvement Leaders' Guide to Involving Patients and Carers*, NHS Institute for Innovation and Improvement, 2005.

[http://www.evidenceintopractice.scot.nhs.uk/media/135286/involving\\_patients\\_and\\_carers\\_guide.pdf](http://www.evidenceintopractice.scot.nhs.uk/media/135286/involving_patients_and_carers_guide.pdf)

*Transforming Participation in Health and Care*, a guide for commissioners, NHS England, 2013.

<http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>

A, Lank E, Maher J. *Communities of Influence: Improving Healthcare through Conversations and Connections*, Donaldson Radcliffe Publishing, 2011.

The Pictor technique is a method for exploring the experience of collaborative working between professionals and patients. Read the article *The Pictor Technique*.

<http://qhr.sagepub.com/content/23/8/1138.short>

## Networks

The Patient Experience Network is a not-for-profit network that supports members involved in improving the experiences of patients.

<http://patientexperiencenetwork.org/>

The Coalition for Collaborative Care is an alliance of people who wish to see more progress in the move towards more person-centred health care.

<http://coalitionforcollaborativecare.org.uk/>