



# Patient involvement in improving clinical services

A guide for healthcare staff



## Why is patient involvement important?

- > Involving patients allows you to understand your service and the care that you give from their point of view. It can identify what is most helpful and what is most frustrating for them.
- > Involving patients in a meaningful way and making sure services are patient-centred is at the heart of our accreditation programmes.

## How can patients be involved?

There are many ways in which patients can be involved and it doesn't have to be difficult or time consuming. The aim is to put in place a process or cycle of continuously involving patients, understanding their views, responding to what patients say and, most importantly, adapting the service and care that you provide as a result.

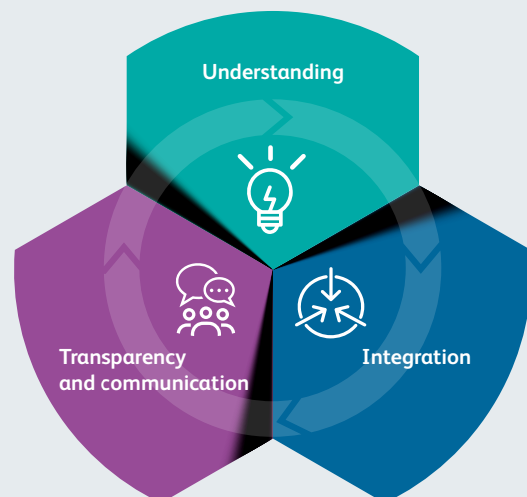
Examples of ways that you can involve patients include:

- > surveys
- > focus groups or longer interviews
- > feedback forms – online or in the clinic
- > online forums
- > inviting patients to strategy or planning meetings
- > co-producing and co-delivering content eg patient/stakeholder information sessions, staff training etc.

Try and use a mix of quick 'asks' that provide a volume of responses and some more 'in-depth' involvement.

Once you have patients' views, make sure you do something with them. Work with patients to put those views into context and add perspective, so you can plan the actions (together).

Once you have a plan that you are implementing and monitoring, tell people! Patients like to know that they are being listened to and can help with communications and dissemination.



## Top 10 tips for optimum patient involvement

### 1. How to ask? Get personal

Your service will need willing patients to start with. How do you find and keep them?

The best way is to ask people on an individual basis and tell them why they are a good fit. This is better than sending out a generic mail out, and you will get more responses. It's still important to put up posters and be transparent. Be clear about the qualities and skills you are looking for and how being involved could benefit them, eg giving patients a voice, development opportunity, training etc.

**‘The patient I would recommend is the noisiest one, the one that has plenty to say’**

Agnes Griffiths, patient focus group member

### 2. Who to ask?

Approach a wide range of people. Consider:

- > aetiology – the root cause of their illness/condition
- > age
- > background
- > patient organisations
- > support groups.

Ask support groups and organisations to put you in touch with patients or put notices in their newsletters or online. Don't underestimate the level of engagement even the smallest of groups may have.











### 3. Barriers to getting involved

Lots of things can put people off:

- > **The task** – think about what you are asking people to do and how you can make it easy for them. Will it be filling in spreadsheets, answering questions, or discussing an issue etc?
- > **The setting** – will you invite patients to a formal meeting or ask them to contribute in a more informal, relaxed environment?
- > **The cost** – it is a good idea to reimburse patients for out-of-pocket expenses like parking or travel. INVOLVE has some useful guidelines on payments to patients.
- > **Contact** – do they need to have email or would they prefer to have contact with you by phone?
- > **Timing** – are they working full time? If so, consider inviting them outside of normal working hours
- > **Accessibility** – does the task/setting need to be adapted to meet the specific needs of some patients to improve accessibility?

If in doubt – it’s OK to ask people what they would prefer – in fact, they’d welcome it!

 Survey?	 Email?
Formal? 	Phone? 
 Informal?	 Computer?
Reimbursement? 	Time? 

### 4. What are you asking for?

- > Be clear about time and your ask
- > Be fair and transparent
- > Are they part of the team or ‘the patient’?
- > When you invite someone, be upfront about what they will be doing and their role in the wider project/improvement initiative, eg your feedback will contribute towards the development of a new patient resource. Do not ask them to be ‘the patient rep’ – that’s actually quite daunting! Instead invite them to be a member of your team looking at ways to make the service better for patients.

### 5. Making it work – ensure everyone is on board

Make sure your whole team is on board and supports and understands why patients are there. Nothing is more off-putting than the person in the room who thinks patients won’t understand anything, are too emotional or are only useful for telling their ‘story’. Do not underestimate patients.

### 6. Don’t assume patients know what you know

- > Organise a pre-meeting briefing
- > Avoid jargon and acronyms
- > Explain the staff hierarchy
- > Do a service walk-through
- > Create an atmosphere that encourages questions to clarify things. A great induction/ starting point would be to walk the patients through your service. It is an invaluable introduction to the way your service works, and the patients will not have seen it from that side.

## 7. Everybody's time matters

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Patients have lives too: jobs, childcare etc and are also juggling health issues on top. However, patients want to be prepared, do their homework and make a difference when they work with you. Make sure you send information well in advance and not at the eleventh hour.

## 8. Keep patients in the loop

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- > Have a dedicated, reachable contact
- > Keep in touch, even when there is no news
- > Always keep your patients informed, even if there is nothing to report. When you do this, patients feel valued and listened to, whereas a lack of communication can lead to patients feeling ignored.

## 9. Expect the unexpected

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- > Listen
- > Value contributions you receive
- > Encourage enthusiasm
- > Ensure your patient engagement isn't just 'rubberstamping'
- > Patients can and do come up with 'off the wall' ideas. Please be open and receptive. Don't get defensive or offer justifications because you want these opinions if you want to bring about change. Ultimately, you are working in partnership with patients towards the same goals.

## 10. A little thanks goes a long way

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- > A lot of patients will feel out of their comfort zone
- > Patients might not be in the best of health
- > Patients do want to help you
- > Time, effort and skills are all going into the support you are receiving
- > Patients are getting involved in something new and out of their comfort zone to give their time, effort and skills to you. It can be daunting at first. Thank them for their contributions and value people's efforts.
- > It doesn't have to be a big thank you, a word of thanks will go a long way.

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If you have any questions, please email [askjag@rcplondon.ac.uk](mailto:askjag@rcplondon.ac.uk)

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