

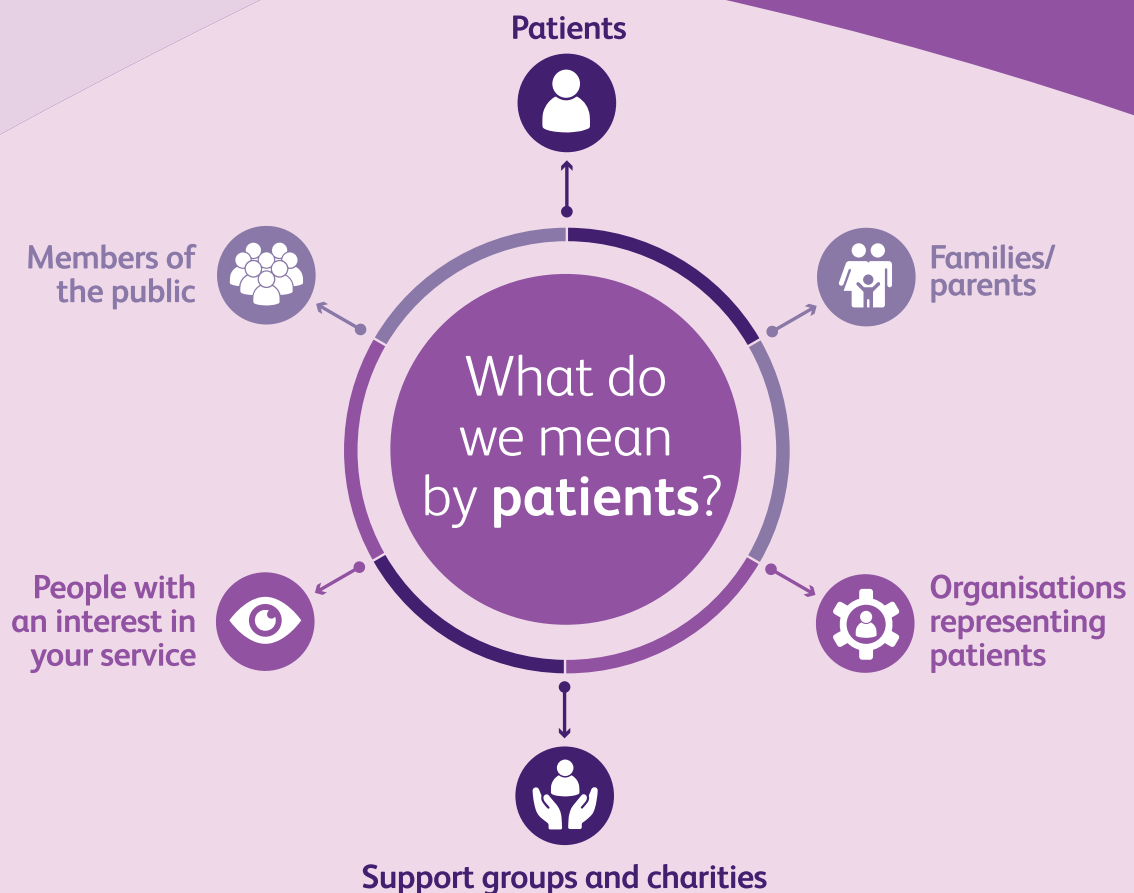


Involving patients in driving up standards of clinical care

A guide for clinicians and practitioners

What do we mean by 'patients'?

When we say 'patients' we mean patients, families, support groups, public etc, the term encompasses a wide group.



Why is patient involvement important?

- > Involving patients allows you to understand the care that you give and your services from their point of view. It can identify what would be most helpful and what is most frustrating for them.
- > At the heart of the Improving Quality in Liver Services accreditation scheme (IQILS) is involving patients in a meaningful way and making sure it is patient-centred.

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:

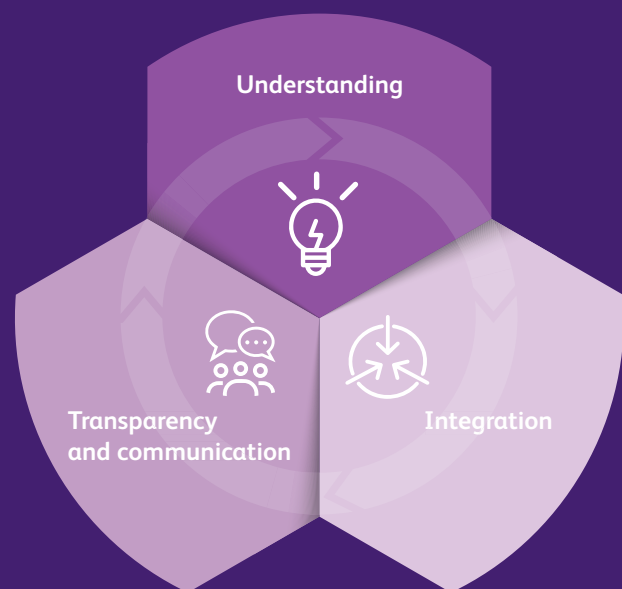
- > surveys
- > focus groups or longer interviews
- > feedback forms – online or in the clinic
- > online forums
- > inviting patients to strategy or planning meetings

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

Once you have patients' views, 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.

The IQILS website has some examples of how other services have involved patients in the knowledge management system.



Top ten tips for optimum patient involvement

1. How to ask?

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

The best way is to ask patients on an individual basis and tell them why they are a good fit. This is better than sending out a generic mailout, and you will get more responses. It's important to still put up posters and be transparent.

2. Who to ask?

Approach a wide range of patients as people from all walks of life have liver disease. Consider:

- > aetiology
- > 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 have.











3. Barriers to getting involved

Lots of things can put people off:

- > **The task** – Think about what you are asking people to do. Will it be sitting doing spreadsheets, answering questions, chatting etc?
- > **The setting** – Will you invite patients to a formal meeting or ask them to contribute in a more informal, relaxed environment?
- > **The cost** – Are you able to pay your patients for their involvement? As a minimum, it is a good idea to reimburse people for any expenses like parking or travel. The Involve website (www.invo.org.uk) has useful further information.
- > **Contact details** – 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.

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?
Payment? 	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 the time commitment. 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 liver unit 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. There is nothing 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

- > Set up a pre-meeting briefing
- > Avoid jargon and acronyms
- > Explain the staff hierarchy
- > Carry out 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

Patients have lives too: jobs, childcare etc and are also juggling health issues on top of all that. However, patients want to be prepared and want to 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

- > Have a dedicated, reachable contact
- > Keep in touch, even when there is no news
- > Keep patients in the loop even if there is nothing to report. When you do this, patients feel valued, but when you don't reply or you go AWOL, patients worry they have done something wrong or are being ignored. Keep patients informed!

9. Expect the unexpected

- > Listen
- > Value contributions
- > Encourage enthusiasm
- > It's not about 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 to welcome these opinions in order to bring about change. Ultimately, you are working in partnership with patients towards the same goals.

10. A little thanks goes a long way

- > A lot of patients will feel out of their comfort zone
- > Patients might not be in the best of health
- > Patients 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 usual area of expertise to give their time, effort and skills. It can be daunting at first. Thank 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 further questions about IQILS please email askiqils@rcplondon.ac.uk

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