



Encourage representatives to voice their views

Tap into the patient perspective

The stories of people who use services can offer health professionals fresh insight, says consultant David Gilbert. But, as he knows from personal experience, it's not easy to make your voice heard.

After recovering from mental health problems, I wanted to improve things for others. I joined my community health council and local chapter of Mind and found myself on various local NHS committees.

They wanted me to be “representative” and go beyond my personal experience, but nobody could tell me what that meant.

What I always needed, but never got, was the support and training to make me an effective patient and community representative, clear in my role and confident in my ability to change things.

Ask any user of services what matters to them and they will have an opinion. Most people involved in trying to improve things for patients are motivated by experience. Some are grateful and want to give something back, others are damaged and demand change.

The obstacle is not that people have an axe to grind but that their sight is partial. If my problem as a patient was not getting access to services, then it would be hard for me to fully understand that this is not the only thing that matters to patients and carers. If I have had poor treatment, how would I know that dissatisfaction is not the norm?

But you don't have to know everything. You need to know broadly what the research evidence says matters to patients, such as safety and access, and become conscious of how your own experience and this evidence relate to each other.

Maybe I shouldn't tell my personal

story at the decision-making table? Not at all. The judicious use of narrative can be a powerful tool. The secret is in when and how to employ it.

Storytelling is not about beating up professionals or emotionally blackmailing people into changing practice. Instead, stories should serve to reframe debates about what matters and illustrate that service users can have valuable insights.

A patient, service user, member of the general public or voluntary sector may first become a lay representative on a project. A mental health service user might be recruited to join a group looking at patient information, or a cardiac patient might be asked to join a panel on access issues. The starting point of their journey into corporate decision-making is usually closely related to their own experience.

From this focused, locally-based, client or topic-specific project, the representative may get invited to do more, such as serving on advisory groups on improvement initiatives, perhaps in areas where they have no particular experience.

When I recovered from mental health problems and got involved in improving services, I felt that I had been let down by the NHS. Whenever I joined meetings, I played the angry consumer, arguing for more of this and better that without having a clue about resource issues, let alone the constraints on professionals.

If user involvement is to work, both sides have to compromise and work on a mutually agreed agenda. To fulfil their central role of keeping discussion focused on what matters to patients, representatives urgently need

systematic support to develop skills and knowledge, including:

- communication skills to present their case to different audiences, such as committees and the media
- understanding of healthcare, relevant to their role and local circumstances
- analytical skills to understand information from the community and deal with data
- “critical friend” skills to deal with professionals, know how to frame questions and tackle challenging issues
- influencing and negotiation skills.

Good representatives are always seeking to sharpen their arguments and focus, looking for the right point at which to make a crucial intervention.

Professionals start to share their enthusiasm and the language spoken around the table becomes more animated. Lay representatives can give permission to others to break free of their own restrictive language. Health professionals have their own tales to relate. We become more human by engaging in debate about what matters to patients.

David Gilbert is director of InHealth Associates, a patient-centred management consultancy. He was head of public and patient involvement at the Commission for Health Improvement and co-founded the NHS Centre for Involvement. He is working with the Department of Health and Croydon PCT to develop a model of patient and public engagement in world-class commissioning. Contact david.gilbert@inhealthassociates.co.uk