

HOPE network summary 14 July 2016

The fifth meeting of the HOPE network was the best attended so far, with 55 members coming together to discuss patient leadership and involvement; it proved to be a lively and stimulating day of learning and knowledge-sharing.

We started the day discussion on the question of “What is a Patient Leader?” Ceinwen Giles, Alison Cameron and David Gilbert shared the stage, weaving together both emotive and informative of each person’s personal “dramatic fall from grace” and an exploration of what encouraged them to get involved with work centred on improving patient care and experience.

David provided a compelling and clear set of criteria for being a patient leader:

- Having a life-changing illness, injury or long-term condition
- Wanting to make change
- Wanting to work in collaboration with professionals to make the change

One of the key themes to emerge was that patients have assets which are often overlooked in patient involvement/engagement work. Alison for instance has previously led large teams with responsibility for multi-million pound budgets and yet her label as a “patient” meant those considerable skills are often ignored by medical professionals. David remarked that we need to move beyond asking patients to simply ‘tell their story’ to having patients at meetings to solve problems in partnership with healthcare staff.

The overwhelming message was that meaningful patient engagement is by its nature uncertain because it removes hierarchies, challenges established ways of working and seeks to ask questions rather than arrive at pre-conceived conclusions. The best way to manage that uncertainty is to provide training for both staff and patients in working with others and clear guidance about respective roles and purpose at the meeting.



Members then sought to assess their own organisations’ level of patient engagement, using a range of established frameworks such as Carmen et al’s [framework for patient engagement](#) and Arnstein’s [ladder of engagement](#) presented by Jocelyn Cornwell.

The exercise served to prove the point that uncertainty is uncomfortable for healthcare organisations and yet it can be necessary for true transformation. The true co-design and production of services requires organisations to accept and to manage uncertainty, whereas traditional patient feedback maintains the paternalistic status quo, where patients are asked to contribute time and energy without having any say over the outcome.

In the afternoon session, Rachel Matthews from the North West London CLAHRC shared ten lessons from her [experience of patient engagement projects](#). One important piece of advice was that organisations and professionals aren't able to harness the assets of patients unless they are allowed to reveal their true identities. She illustrated the point beautifully with a real-life example. Rather than saying there were four patient representatives at a meeting, she listed their professional identities (project manager, engineer, cabin crew, artist).

“Brilliant day – very glad I’m now part of the HOPE network”

“Such a great buzz in the room”

“This was an excellent, vibrant, full-on day – very much enjoyed it”

As well as providing valuable insight, Rachel was also able to offer practical solutions to a range of problems raised by members. She has recommended the following papers to members of the network who are interested in the work CLAHRC have done on patient engagement:

- [From tokenism to empowerment: progressing patient and public involvement in healthcare improvement](#)
- [A systematic review of evidence on the links between patient experience and clinical safety and effectiveness](#)
- [Patient and Public Involvement in Healthcare Quality Improvement: How organizations can help patients and professionals to collaborate](#)

The final session of the day saw four members give elevator pitches showcasing innovative work around patient engagement which they wanted to share with colleagues:

- *Lesley Goodburn, Midlands and Lancashire Commissioning Support* - [Homeward Bound](#)
- *Lisa Anderton, UCLH* - toolkit for patient engagement
- *Sarah Higson, Ipswich Hospital* - Adopt a ward: initiated by patient leaders
- *Jenny Pennell, East and North, Hertfordshire NHS Trust* - Information posters, developed by patients and staff, they won the access to information award at PENNA this year

It was fantastic to be part of such an engaging meeting, full of ideas, expert advice and practical support. The feedback from attendees reflected that, with 100% rating the external presentations as good or excellent, and 96% rating the meeting as good or excellent overall.