The
Point of Care
Foundation

Report of the 11th HOPE network/South West regional meeting

Taunton

24 April 2018

Introduction[1]

On 24 April, the HOPE network met for its first ever regional meeting. The meeting was designed to enable as many members to engage with the network as possible, especially those who are not usually able to join us in London, as well as to connect with local networks. The meeting took place in Taunton and was held jointly with the regional patient experience network for the South West region. It explored the recurring and important theme of engaging patients and staff.

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[1] HOPE meetings are conducted under Chatham House rules, which means we treat the proceedings as confidential and don't attribute remarks to individuals outside of the meeting. However, we do want to share the content of discussions and resources produced for the meetings with the wider network and with others with an interest in patient experience. To resolve the dilemma, following discussion with members at the March meeting we have agreed the following process:

1. The Point of Care Foundation (POC) team will write up and circulate the draft report of the meeting to everyone who attended the meeting, including external guests, inviting changes and comments to be sent back within 10 days.
2. If people choose not to comment and don't respond to POC within 10 days, POC can assume it has their consent to publish.
3. Following consultation, POC will revise the draft report and check back that the person/people who made the comments is/are satisfied with the changes.
4. POC will post the report on the HOPE webpage on: www.pointofcarefoundation.org.uk

Learn, Borrow, Steal

Signlive

Claire Jukes and Jayne Glynn from Plymouth shared the Signlive app, which they are using to improve services for patients who are deaf. At the moment they have an average of 27 British sign language bookings per month, which is increasingly costly. In addition to the cost, the limited availability of British sign language interpreters has led to a number of patients missing their appointments, and increases the risk of delays to emergency treatment. Signlive is an app that can provide an instant video link between the patient and a sign language interpreter. A lot of the hard work on this project has been in winning over the deaf community, which was, initially at least, concerned about this change. The project has been an overall success and has led to mostly positive feedback and a reduction in the number of face to face interpreter bookings.

Chatterbox

Becky Parish from Gloucestershire shared her work on engagement with younger people. Chatterbox is a booth, similar to a photo booth, with touch screens and video-recorded questions to engage with young people and gather feedback. They have taken the Chatterbox around Gloucestershire, setting up in places such as market squares and shopping centres. This has been a very effective way of engaging with younger people

Young people’s guidance for staff

Lucy Nicholls from Somerset Partnership NHS Foundation Trust told the story of how she had worked with young service users to design a leaflet on what staff can do to engage and help young people using the service. This process overturned the normal dynamics of the trust’s relationship with young people.

End-to-end service tracking

Sam Holden from NHS South Devon and Torbay Clinical Commissioning Group talked about tracking individual patients through healthcare processes from end to end, from the emergency service phone call, through the ambulance service into A+E. They are keen to adapt this to other environments.

Sharing compliments

Karen Holden from Musgrove Park Hospital wanted help from other members with how to use and share patients’ compliments.

Why we need to think differently about engaging doctors in patient experience – Dr Joanne Watson

Joanne is the Deputy Medical Director at Torbay & South Devon NHS Foundation Trust. She started by reflecting back 10 years to 2008, and the question of what quality looks like in the NHS and how patient experience fits into it. In 2008 patient experience was typically viewed as nice but not necessary, and too expensive. Today it has started to become more ingrained in the vocabulary of quality, but a lot of the same conversations are still ongoing, and ultimately, in NHS trusts, patient safety trumps everything else.

Joanne urged members to walk in doctors' shoes. All doctors, she said, come to work to do a good job – to care for people, to improve patients' lives, and to improve the health of the patients they work with. But there are so many other factors that affect doctors:

- Care is enormously complex, and continues to become more so
- Medical training is still very similar to how it was 100 years ago, and hasn't kept up to speed with changing relationships between patients and staff
- Staff are taught paternalistic care; doctors feel obliged to offer solutions
- Team-working is still not the norm in healthcare
- Medical staff are highly trained as specialists – but are not trained as leaders
- There is a huge fear of failure – with every incident creating a feeling of "that could have been me"

Joanne urged members to relate to their medical colleagues as human beings, reflecting on her experience of each new year when junior doctors join her trust, and how young and initially timid they are when they first arrive.

Because trainees change job every few months and rarely stay put for long, it becomes even more important to make sure that they feel part of a team that can offer them the security they need. Joanne talked about how adults currently reach mental maturity later and later in life. Each generation reaches mental maturity later than the last. So the current generation of junior doctors are in the early stages of their career whilst still immature in some aspects. "You need to look after junior doctors, you need to protect them."

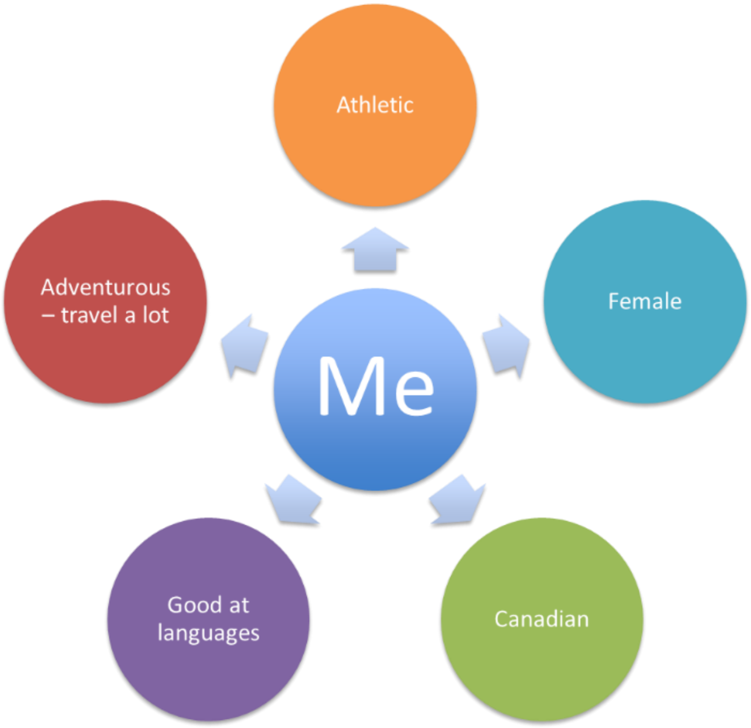
'The Doctor' by Sir Luke Fildes - 1851

Joanne ended by sharing this painting, 'The Doctor', painted in 1851 by Sir Luke Fildes – himself a doctor – to illustrate how similar medical training is to 100 years ago.

She argued that patient experience should be threaded throughout medical training, rather than taught in small blocks and modules. She wanted doctors to be better prepared for the reality of practice: as expectations grow, so does the pressure on doctors. It’s important to acknowledge and work with the fear of failure amongst colleagues. She said that when working with doctors it’s important to be gentle where we can, and even more important to make sure that we celebrate compliments, rather than just focusing on complaints. The first step to engaging doctors with the work of patient experience managers is to understand the doctors’ own experiences, and the situation they are in.

Patient Involvement and Leadership – Ceinwen Giles

Ceinwen began this session on patient involvement by asking the delegates to reflect on themselves and how they think of their identity. Everyone in the room was asked to draw a circle of self following Ceinwen' s example below. This was used as a starting point for thinking about how skills and self-identity fit together.



Asset Based Community Development – ABCD

This is a method based on the basic idea that a community, or patients in the healthcare context, can be resources, and that everyone has something to contribute. A key part of this goes back to the circle of self diagram, and the importance of separating out the identity and stereotypes from the assets within any member of the community.

Ceinwen then told the story of Shine - the charity that she co-founded – and how it has utilised asset based community development to its advantage. As they developed Shine, they recruited volunteers with strong individual skills, as well as cancer. What they didn't realise is that they were also recruiting patient leaders. Some examples of the skills that their volunteers brought with them were: Someone with chronic leukaemia who was also an organic skin cream entrepreneur; someone with Hodgkin lymphoma who was also a web designer.

The resources that the volunteers bring to shine have proved vital. Many important parts of their work would never have been explored or achieved without the skills of their volunteers. Ceinwen talked about how a lot of these skills are only seen when you actively look beyond the diagnosis that initially brings the volunteer to you. Shine uses this expertise, plus their online community, to develop their annual events: they survey their community to develop the themes and what they want as part of the event; then at the event registration they ask them again what they would like from the sessions.

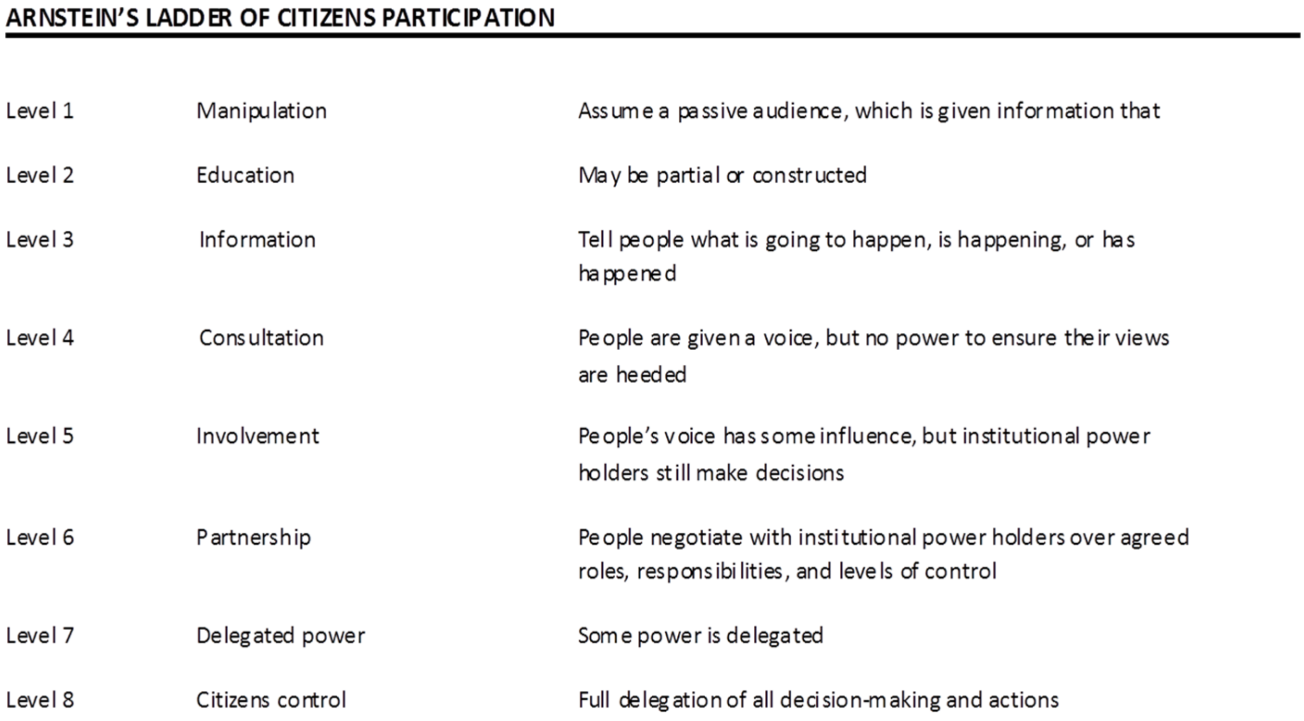
Ceinwen then went through the principles that Shine use to shape their work with volunteers:

1. Time is needed to build trust, and participation should also be time-bound
2. Things work best when we bring people together around common cause
3. Community connectors are vital to outreach as they're motivated and 'reach' into their networks – we work with a lot of other organisations.
4. Any event we run needs to respect the experience of people and also energy levels
5. Experience is everything: Attention to detail, to demonstrate care, to make it unique. We aim to have good food and drink – and swag!
6. Ongoing communication and feedback is needed. If people take the time to give you feedback, they want to know they've been heard.
7. Everyone is equal - need to create conditions that ensure all voices are welcomed and listened to.
8. Meet people where they're at - on their terms, in ways that suit them, on things they care about. We hold meetings, as much as possible, at dates and times that suit the people we serve.

Frameworks for engagement – Jocelyn Cornwell

Jocelyn Cornwell led the second half of this session, based around different frameworks for engagement.

The ladder of engagement is the most common framework, this is reproduced below. Most organisations will find themselves between 1 and 4. The delegates were asked to work out where their organisation would be on the ladder, and how this varies due to the context of the work. This discussion explored how certain levels of engagement are necessary for different types of work, and sometimes the levels around 2-3 are vital, and level 8 is not possible or wanted.

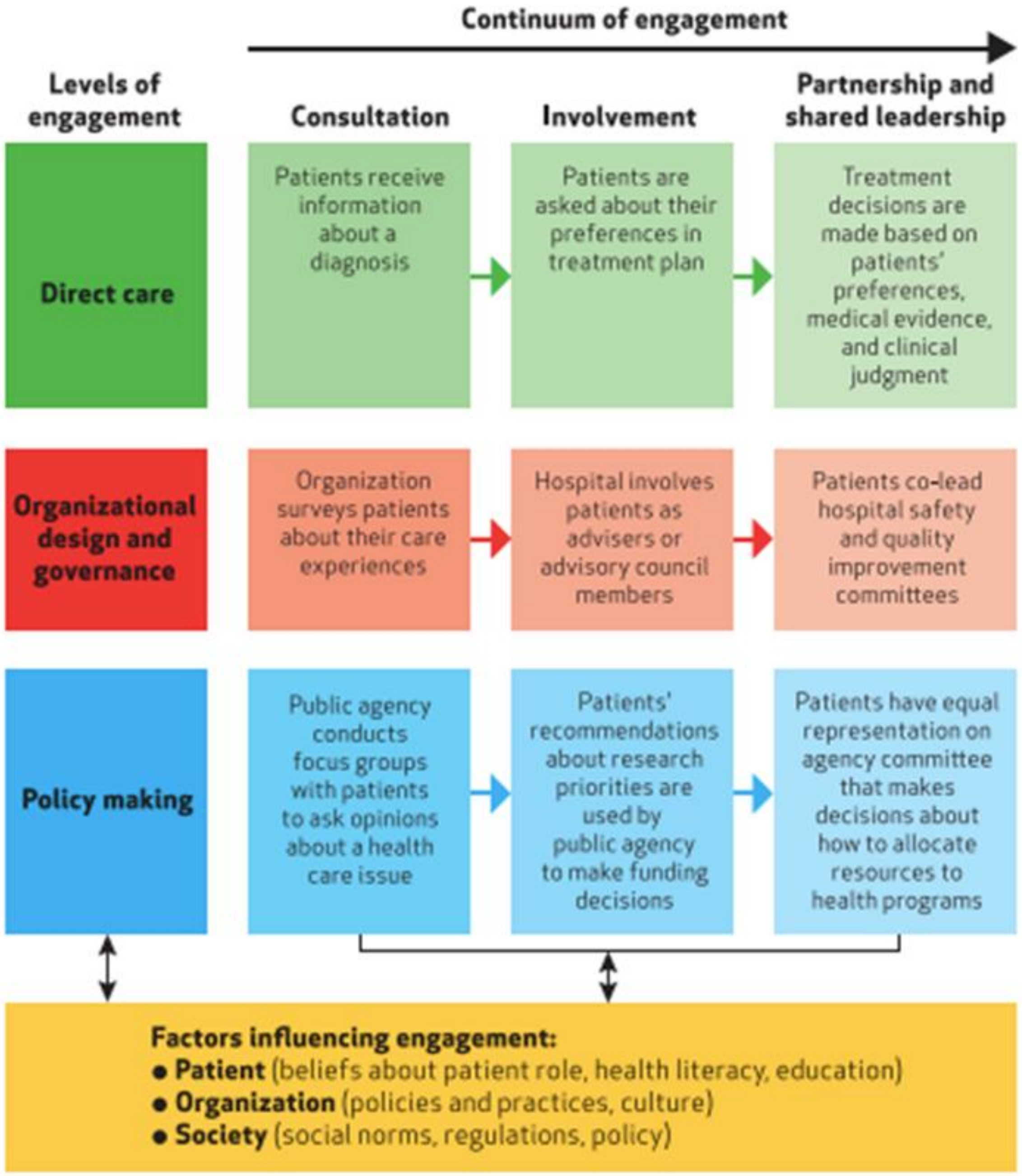


ARNSTEIN'S LADDER OF CITIZENS PARTICIPATION

Level 1	Manipulation	Assume a passive audience, which is given information that
Level 2	Education	May be partial or constructed
Level 3	Information	Tell people what is going to happen, is happening, or has happened
Level 4	Consultation	People are given a voice, but no power to ensure their views are heeded
Level 5	Involvement	People's voice has some influence, but institutional power holders still make decisions
Level 6	Partnership	People negotiate with institutional power holders over agreed roles, responsibilities, and levels of control
Level 7	Delegated power	Some power is delegated
Level 8	Citizens control	Full delegation of all decision-making and actions

The other framework for engagement that was explored was Carman's framework for engagement (pictured below). This provides a more varied set of dimensions for patient engagement, and enables different types of engagement, against different levels. Jocelyn asked the delegates, where they felt their organisation was on this framework, and what they would need to do to move towards the right of the chart.

A Multidimensional Framework For Patient And Family Engagement In Health And Health Care



Levels of engagement	Consultation	Involvement	Partnership and shared leadership
Direct care	Patients receive information about a diagnosis	Patients are asked about their preferences in treatment plan	Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment
Organizational design and governance	Organization surveys patients about their care experiences	Hospital involves patients as advisers or advisory council members	Patients co-lead hospital safety and quality improvement committees
Policy making	Public agency conducts focus groups with patients to ask opinions about a health care issue	Patients' recommendations about research priorities are used by public agency to make funding decisions	Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs

Factors influencing engagement:
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

Network Matters – The Point of Care Foundation and Sam Holden

The final session of the day focused on the local network, what steps it can take to continue to grow and support its members, and what The Point of Care Foundation can do to help support its success. This session was co-led by Sam Holden and the team from The Point of Care Foundation. Those present were asked if, as a starting point, they would like to be part of the national HOPE network as well as the local network (if they aren't already). There was universal approval for this in the room (although in light of GDPR, those wishing to be part of the HOPE network will need to fill their details out here). The local network is keen to grow, and one suggestion for facilitating this was a change of regular venue. The current regular venues are in Exeter, but the network would be happy to expand into the West Country if there was interest. The next meeting, in June, is planned for Exeter, but the September meeting could be at any location.

Another key element to the network's success is the quality of speakers that it can attract, especially as the south west is so far away from the rest of the country. It was also mentioned that one of the strongest features of the network was how it operates as a safe space, where comment is free.

The discussion then turned to what the network needs in order to ensure its success, and what The Point of Care Foundation can do to help support the local network's growth. Ideas of actions to support its continued success include:

- It should continue to be a safe space
- It should offer a forum for problem solving
- Local networks could come together once a year as a larger regional network
- The overall network should cover the South West and Wales
- It should meet less frequently and combine the local networks
- It should Include admin and support staff
- A Facebook group was suggested to ensure the network continues to work outside of official meetings

What link with the HOPE network could be beneficial?

- Maybe the HOPE network holds info of all local group networks
- A training course – Foundations in Patient Experience was mentioned in this context