

# Report of the HOPE network regional meeting

## Cambridge

### Introduction<sup>1</sup>

On the 11<sup>th</sup> July, the HOPE network met in Cambridge for its second 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. It explored the recurring and important theme of engaging patients and staff, with the focus on doctors.

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<sup>1</sup> 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 with the wider network and with others with an interest in patient experience. Following discussion with members we have agreed the following process:

1. The Point of Care Foundation (POC) team writes up and circulates a draft report of the meeting to everyone who attended, including speakers, inviting changes and comments to be sent back within 10 days.
2. If people comment, POC takes account of what they have said, revises the text and checks it with them, allowing a 10 days for a response
3. If people don't respond within 10 days, POC assumes it has consent to publish.

POC includes links to reports in newsletters and posts reports on the HOPE webpage on: [www.pointofcarefoundation.org.uk](http://www.pointofcarefoundation.org.uk)

## Learn, Borrow, Steal

**Talk to me** – Shahid Sardar – Princess Alexandra Hospital NHS Trust

Talk to me is a **micro teaching module on communication skills** with a teaching booklet, slide set and audio developed to accompany the training. The project was a collaboration between speech and language therapists, the training team, nursing and patient experience. Frustrated, by only being called in for clinical issues, and not to help with communications more generally, the speechies approached patient experience to help increase their reach and referrals to speech and language therapists. The group developed the teaching booklet to illustrate how we are all perceived differently dependent on our preferred communication style, two case studies on communication failings, a patient voices story and other communication tools. The teams have taken training directly to staff on the wards using the *Talk to me* booklet, you get a pin badge and a social media selfie as a reward. As part of this closer collaboration with speech and language therapists Shahid has learned that they don't like being referred to as SaLT but rather as "speechies."

**It matters to me** - Shahid Sardar - Princess Alexandra Hospital NHS Trust

The most recent National Cancer Patient Experience Survey results for PAH showed that late treatment effects, support and contact post discharge were two of our biggest issues and as a result, following meetings with the STP, the patient experience team secured funding from the Cancer Alliance, supported by the Sustainability and Transformation Partnership (STP), West Essex Clinical Commissioning Group and the Patient Panel to develop a conference intended to involve the public in shaping local cancer services. Workshops took place on the most pressing issues in the National Survey and from patient experience data on five subjects:

- Management of side effects and late effects
- Life after the challenge to develop a better post discharge support process
- Young people affected by cancer – as a patient, carer or family member
- Money matters – financial challenges as a result of diagnosis and treatment for cancer
- Who cares – the role of carers including younger people

Out of the "It matters to me" event they have developed specific actions, which are going to be implemented together with the Head of Cancer at the Trust. Shahid said the key lessons that they learned from this process is that the STP are willing to help, and are interested in patient experience.

**Inclusion as standard** - Simon Howard - Equality, Diversity and Inclusion Lead – North West Anglia NHS Foundation Trust

The aim of this scheme is to remove the burden of worry people with special needs can feel about using services that their personal needs will be ignored, as well as to reassure them that even if their needs are not currently met, there is a system in the trust that supports staff to learn and adapt.

To ensure the project's success, the trust designed services together with the people they were trying to support. They began by setting up coproduction groups, and specific groups for deaf and hearing loss, LGBTQIA, and Autism.

The inclusion as standard scheme follows 4 steps:

1. A staff member (any staff member from porters to consultants) to complete a report, on something that has gone well, or a problem they have encountered with regards to inclusivity
2. The report is sent first to the Equality, Diversity, and Inclusion Lead, and then to the relevant coproduction subgroup, who can make a request that a policy be adapted.

3. The evidence is collated and used to support the Trust's Equality Delivery System 2 submission
4. Departments and Wards that achieve the greatest levels of inclusivity are then rewarded with Inclusion as Standard awards. They also take into account whether the ward or department has managed to support groups who are outside of the Equality Act such as homeless people. This acts as both an incentive to the Wards, but also works to reassure patients.

## Patient Involvement and Leadership – Ceinwen Giles

### Asset Based Community Development – ABCD

ABCD is based on the idea that a community, or patients in the healthcare context, can be valuable resources, and that everyone has something to contribute. Often when running a project we look at the deficit – the problem that needs to be solved – but you can flip this on its head and look at the assets that the people affected by the problem have.

Ceinwen shared the story of Shine – the charity for young adults with cancer 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, such as someone with Hodgkin lymphoma who was also a web designer. What they didn't realise at the time was that they were also recruiting patient leaders.

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.

Shine uses the following principles 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. Go to where people are - even if that's a pub.

## Frameworks for engagement – Jocelyn Cornwell

Arnstein's 'ladder of engagement' is the best known framework in engagement (reproduced below). Jocelyn asked the delegates to consider where their organisation sits on this ladder. Every organisation will have areas /departments/units that sit at different levels of the framework.

### **ARNSTEIN'S LADDER OF CITIZENS PARTICIPATION**

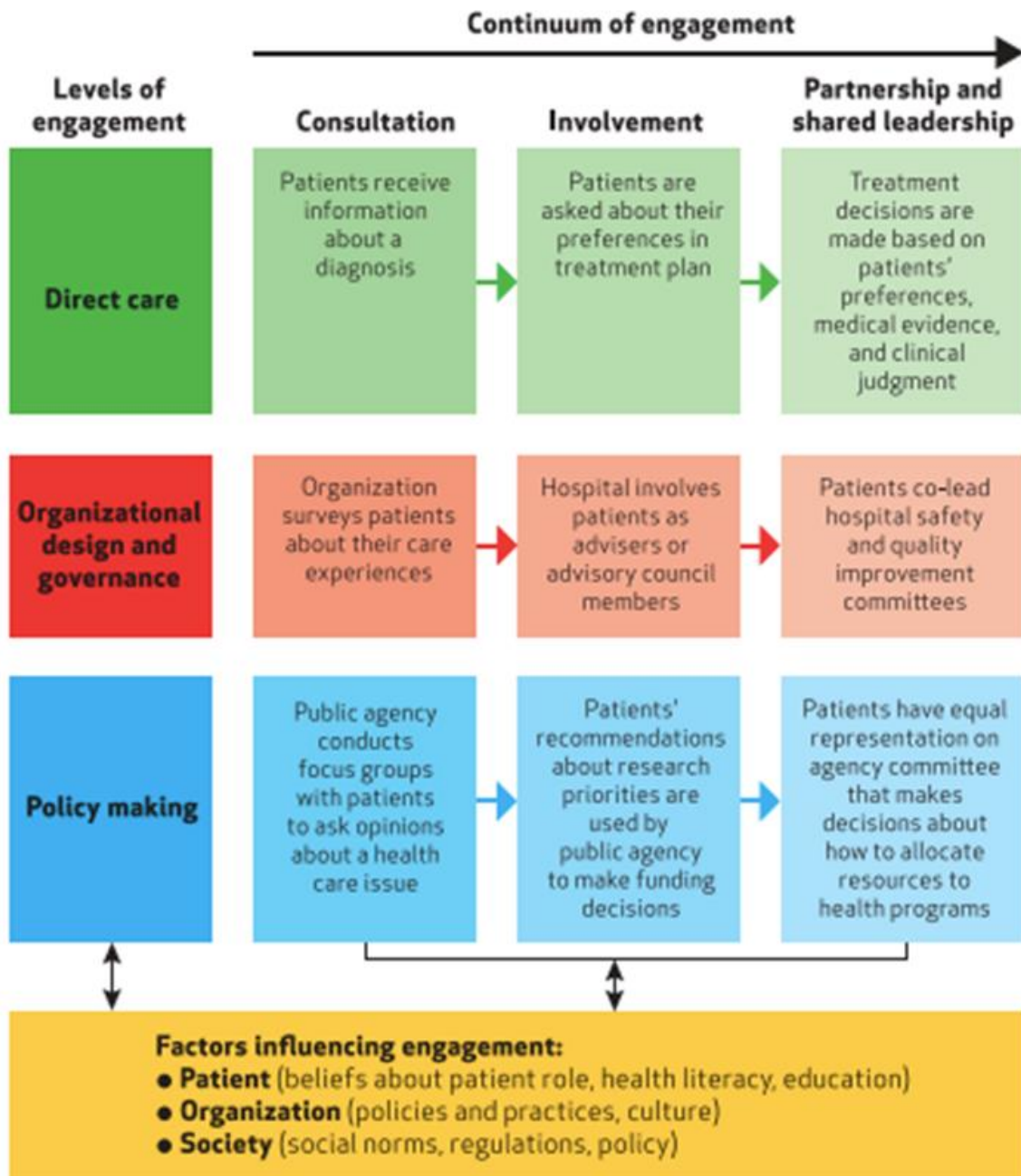
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Level 1	Manipulation	Assume a passive audience, which is given information that
Level 2	Education	May be partial or constructed
Level 3	Information	Tell people what is going to happen, is happening, or has happened
Level 4	Consultation	People are given 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

Carman et al's framework (pictured below) offers an alternative framework that better reflects the complexity and multi-dimensional nature of engagement. Within healthcare this dimension can be very important as it reflects the distinction, for example, between a patient being involved in their own care and patients being involved in service improvement.

Insert references for both frameworks

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



## **Medical Engagement - Dr Roman Romero-Ortuno**

*Consultant Geriatrician – Cambridge University Hospital NHS Foundation Trust*

Dr Roman Romero-Ortuno joined us to speak about his experience of the patient experience agenda, as a Consultant Geriatrician. Roman began by outlining the typical setting in which he works, which is a ward for older people at Addenbrooke's hospital. At Addenbrooke's all older person admissions are routinely screened and assessed for a variety of conditions such as frailty and cognitive impairment in order to determine if they should be admitted to the care of the elderly ward.

Roman was keen to bust some myths about geriatric medicine, such as the impression that most older people lose their normal functional ability during their stay in hospital, in fact the majority regain the abilities. Older patients typically have a combination of conditions which adds complexity to their care. The ward handles this complexity through multidisciplinary team (MDT) working. The MDT develops personalised patient centred care plans for each patient, but they also involve patient and their families in designing their own care. Many MDT members champion the patient experience. One HOPE member suggestion was that this could be through dedicated patient leaders in the future.

Roman made the distinction between 'official and 'non-official' patient experience domains.

### **Official patient experience**

The primary form of official patient experience is metrics for the CQC and CQUINs. Some of these metrics are useful and relevant but some have methodological challenges in geriatrics. For example, the Friends and Family test in care of the elderly wards can only gather a relatively small number of responses, which can affect the representativeness of the results.

The other main official patient experience work is with the Patient Advice and Liaison Service (PALS). There are important local initiatives towards capturing and reporting compliments and positive feedback, as well as concerns and complaints.

### **Non-official patient experience**

Roman described the non-official patient experience work they do on the geriatrics wards, which has an important impact on patient experience. For example:

- Brownie points scheme - which is awarded (with a real chocolate brownie) to the MDT member who is going the extra mile in helping patients and carers.
- They recently received a grant to refurbish one of their older wards, which has led to an environment which is much friendlier to older patients.
- Every Christmas, a choir come onto the care of the elderly wards to sing Christmas carols.
- They run seated dance and movement workshops for the patients on the wards <https://vimeo.com/130622414>
- *You made a difference award*– The hospital Chief Executive and Divisional Chair comes to the ward and brings cake and awards a certificate to the staff. The award

aims to reward and recognise both teams and individual staff members who have 'made a difference' to patients, visitors or colleagues.

- *Use it or lose it* – an awareness campaign to reduce deconditioning in elderly patients.
- The *#endpjsparalysis* campaign.
- John's campaign – for the right of carers to stay with people with dementia.
- The blue wristband policy to minimise ward moves within the hospital.

Roman finished his session by bringing the discussion back to the starting theme - of how the patient experience agenda is experienced by doctors. His final summary was that:

- Doctors are generally interested in patient experience.
- Doctors can be critical of methodological problems with 'official' metrics (definitions, sampling, compliance, etc.).
- A lot of emphasis on 'stick', less emphasis on 'carrot'.
- A lot of emphasis on 'official', less on 'non-official'.
- Many doctors are willing to collaborate with patient experience managers, especially in specialties where there is established multidisciplinary working such as geriatrics.



## **Network Matters**

We were joined in Cambridge by Claire Cowley and Annette Agetue-Smith from NHS England, who work with Heads of Patient Experience across the East of England. Claire explained their roles, and the future merger between NHS England and NHS improvement.

This final session focused on how the HOPE network and The Point of Care Foundation (POCF) can help support local networks and help local members attend HOPE network meetings.

There was a debate about what we define as a region, as there are many definitions such as using NHS England boundaries, historic counties etc. The view of The Point of Care Foundation is that it's about reaching people who can't easily travel to London. One of the geographic challenges mentioned by the members is the remote nature of coastal regions, and the difficulty they have in travelling to London based events.

The delegates and POCF discussed whether there are better locations for an East of England meeting to be hosted, and the consensus in the room was that it is just as easy to travel to London as it to travel to any of the cities in the East of England. We discussed webinars as an option but due to technical concerns (the NHS firewall), and lack of an opportunity to meet other members in person, it was viewed that it would not have anywhere near the same impact as the meetings themselves.

One of the members suggested a bring a buddy initiative where each member invites another head of patient experience to join the network and attend the event. This sparked a discussion around precisely who the network is for, as often members want to invite a colleague but are uncertain whether the colleague is right for the network. Jocelyn clarified that the network is designed for staff who have to work on patient experience on the ground.