The
Point of Care
Foundation

Report of the 10th meeting of the HOPE network

Royal College of Anaesthetists, London

14 March 2018

Introduction

In March, the HOPE network revisited the topic of measuring patient experience for the third time since the network started. The fact that we keep coming back to this topic, indicates how important, how controversial and how challenging it remains.

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

Data, stories and feedback: how can we make measurement work for us?

Learn Borrow Steal (and a Worry)

We know from members' feedback that the session where members share what they are doing with each other is very popular, so this time we scheduled Learn Borrow Steal for a full hour at the beginning of the day and included Worry as a new category. We had four items this time including one Worry (see slides here).

1. Volunteering in the NHS for Children and Young People. Amy Maclean, from Birmingham Women's and Children's Hospitals, spoke about becoming a beacon site for *#iwill,* the national campaign for volunteering. The Trust is holding a regional meeting about it on 14th May; HOPE members are welcome to attend and can find out more dates by writing to amy.maclean@bwnft.nhs.uk.
2. *#last1000days, #endpjparalysis, #redtogreendays*. Katie Moore from Nottingham University Hospital presented three exciting, inter-related, bottom up initiatives that have really engaged staff across the Trust, and represent a sea change in commitment to improve patients' experiences within the organisation.
3. Have your Say. Lara Harwood from Hertfordshire Partnerships University NHS Trust presented her work trust reviewing and revising the current feedback mechanisms in acute mental health settings.
4. A Worry: Rachel Cave from Sussex Partnerships, a mental health and learning disabilities trust, led a discussion on how she might improve the level of involvement from patients who live in rural communities.

Always Events: the right behaviours always and everywhere

Lisa Anderton, UCLH and Dominic Mundy, Central London Community Health (CLCH) (See slides here (from page 25))

Always Events are 'things that should always occur when patients interact with healthcare professionals' (taking the Never Events and flipping it on their head). The national effort to implement Always Events is led from the top by Jane Cummings, Chief Nurse, NHS England in association with the Picker Institute and Institute for Healthcare Improvement (IHI). The method for implementation is co-production and co-design in conjunction with the 'model for improvement' using small tests of change. Picker and the IHI support data collection, provide coaching and mentoring and share their expertise. There are currently 97 sites doing Always Events in England, of which 13 are in learning disability services and autism.

What do Always Events do?

- They put patients at the heart
- They are connected to core purpose
- The idea is to improve the right things together
- They should be connected to the vision for the trust

The two contrasting case studies were from a Trust where the work on Always Events has been led from the top by the Chief Nurse and a Trust where the service chosen to pilot implementation of Always Events was selected by the patient experience co-ordinating council.

Questions and selected key points in the discussion with Lisa and Dominic

1. *Q: How valuable is it to have support from the top? How necessary?*

   A: VERY. Tips: Make sure that your Chief Nurse knows about and supports the Always Events

2. Q: *How much time does it actually take?*

   A: One trust had a dedicated programme manager doing the work for six months who was embedded in the patient experience team. In six months they identified the key pilot areas and the key changes required and then took another six months to make the changes. Tips: it takes at least three months to understand Always Events and choose the area of focus. Timescales are difficult to predict.

3. Q: *Are Always Events linked to staff experience? Do you look at staff as well as patient experience?*

   A: YES – the two tie together

4. Q: *Who are the right people to have on the team to do this work?*

   A: The internal Quality Improvement team if there is one. The communications team. Patients. Doctors as well as the other professionals working with patients.

5. Q: *How do you embed the changes once you have made them?*

   A: Quarterly follow up phone calls with staff and patients; as soon as the PREMS results start to drop off then they look again; embed the work in training for Band 6 nurses.

   A: Determination and bloody mindedness; forcing Always Events into other people's objectives.

6. Q: *How do you engage staff who are terrified and overwhelmed*?

   A: This is always one of the biggest battles for all QI programmes. It takes a great deal of time and energy and it's crucially important to get the right people in the room to start with. Be realistic about time scales: it takes at least 12 months to get to results that you can report. Start small and get results in one area before trying to spread it to others. Co-design and co-production basically means involving patients. People are anxious that they won't make enough of a difference and the scale of the changes will be very small. Conversely, they are also anxious that patients will want to see very big changes. At CLCH, the anxieties were not realised in practice. When it came to it, the nursing staff welcomed standardised scripts to use with patients because they realised they did not always know how to answer patients' questions.

7. Q: *How do you identify areas where you're likely to have success? Are there hallmarks to look for?*

   A: You need to listen carefully to sort out what the problem is that you're trying to solve.

8. Q: *Can Always Events help with longer term pressures?*

   A: Yes, possibly, but you still need to create the headspace to do this. The attraction for staff is that this might help with frontline issues and working with patients does really energise staff.

9. Q: *How achievable is it to implement Always Events with very limited resources in a patient experience team?*

   A: Difficult, but you might be able to use volunteers if they're trained, so think about recruiting volunteers if you've got a good volunteer service.

   A: It is do-able but you need to plan wisely and take the clinical lead or nursing lead with you.

Hearing the patient voice at every level: carrying feedback into the heart of care. James Munro, CEO, Care Opinion and Paul Sanguinazzi, Nottinghamshire Healthcare.

James spoke about his perspective on patient feedback based on the experience of running Care Opinion for the last ten years. He began with a quote from Don Berwick: we should strive to "*hear the patient voice at every level – even when that voice is a whisper*".

James talked through some of the issues that confront HOPE members and others when they try to amplify the voice of patients:

- Clinicians are ambivalent about patient feedback and often complain that "*patients don't understand what we do*" as doctors and nurses. James pointed out that it's not a patient's job to understand the staff.
- Laura Sheard in a recent paper argues that much of the feedback that is being collected is focussing on the wrong things and that staff feel overwhelmed by the pressure to act on it.

In line with Laura Sheard's findings about the barriers to using feedback to make change, and how to overcome them, James advocated asking ourselves these questions before we collect feedback from patients:

- Do patients know anything about their care?
- Are we willing to act on what they know?
- Are we able to act on it?
- If so, is it on our own or with others?
- If it is with others, is the wider organisation with us?

He argued that despite the attachment in the NHS to data and evidence, all clinicians are human beings and therefore open to, and affected by, stories. It is not only clinical staff who want feedback from patients, non-clinical staff do too. Care Opinion has found that when patients provide critical feedback, they want to hear from a clinician or someone who leads the service they have been affected by, rather than the PALS service, the Patient Experience Manager or a Communications Person.

Paul Sanguinazzi described in detail the thirteen-year long programme of creating a culture that is more responsive to service users in his trust, telling a great story of how he went about getting responsiveness to patients embedded in the culture. Some of the things he has instigated are:

- Including a session on service users and feedback in the induction programmes
- Including responding to feedback in leadership development and training
- Using volunteers as partners
- Making all the feedback that they obtain from the public, from staff and from patients visible online
- Having very clear expectations of individuals and teams that they should be accountable to the board for their responsiveness to patients. (The trust has a contract with Care Opinion which means all the feedback patients post about their experience is open to the public, which provides the openness)
- Using a peer service to investigate and place all comments and complaints on the trust website, regardless of what they say
- Phasing reports, to the Board, one per service each month with the general manager for the service and the involvement lead presenting together

- The Board receiving a patient voice report that covers key issues and actions planned and reviewing it at three and twelve months intervals

Paul noted that over time, the discussion at the Board has changed from an obsession with response rates to much more of a focus on the content of what patients are saying. The change of culture is in the wider themes for each service that goes to the Board. Every service accounts to the patient experience team for what they've achieved. "*The stuff that has really worked is the bit about stories."*

The main message from the session: changing the culture has to be done bit by bit and is about making the changes incrementally and trying to maintain momentum.

Patient–focused improvement in end of life care and medical engagement. Bev Fitzsimons, The Point of Care Foundation and Dr Emma Wilkinson, consultant, Ashford & St Peter's Hospital

The session showcased work to improve end of life care on a general medical ward at Ashford and St Peter's Hospital (ASPH), part of the Point of Care Foundation's 'Living Well to the Very End' collaborative learning programme.

Dr Wilkinson described her experience from the beginning of the project when she wanted to find out "Why we don't treat all our patients like our own loved ones?" to the point they have reached now where she has a much better idea about what patients experience on her wards and is beginning to put the changes in place.

She reflected on the reasons why staff don't look after patients like their own loved ones:

- Time
- Don't know how
- Hierarchies
- 'Jobs worths': "*that's not my job …"*
- Staffing levels

She has started to think about how we measure the quality of care and seeing that at the moment what is measured is what trusts /the Board want and need, not necessarily what patients want. At ASPH the team on her wards has decided to ask patients *"What matters to you*?" and to post the answers every day on a board above the patient's bed so that the staff and visitors are all aware of what the patient says.

Emma gave examples of things that the team discovered by standing back and doing direct observations of care and by shadowing their own patients. They found that:

- Some patients are asked to explain their social history nine times. Why?
- Every older person on the ward was being put into incontinence pads straight away because the staff did not know whether they were incontinent. As a result of the programme they are putting a stop to the practice and starting *#loseapad*
- Appreciating the role of health care assistants more and involving them in hand over the first time.

The session ended with a conversation with Emma about medical engagement in improving patient experience from which the main messages were:

1. Use measures to talk to medical colleagues about driving change
2. Tailor the message to the audience
3. Reflect on what we mean when we talk about 'medical engagement' - perhaps we should be talking about engaging *everyone* as individuals. The point is to ask what does this job mean to the person? It is about individuals not categories of people.

Final word from the session: *"What I can do as a doctor is not the same as what I should do. Why don't we all ask what patients would like?"*