The Point of Care Foundation

Presenting Narrative Information to Drive Improvement

AHRQ research meeting “Advancing the Science and Implementation of Patient Narratives”

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7th Oct 2021

Disclosures

I have no conflicts of interest, financial interest, or sponsorships relevant to this activity to disclose.

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We are working to radically improve the way people are cared for and to support the staff who deliver care

Improving the way we are cared for

because understanding and responding to the needs of all people is what delivers the highest quality care

Supporting healthcare staff

because delivering high quality care is only possible if staff get the practical and emotional support they need

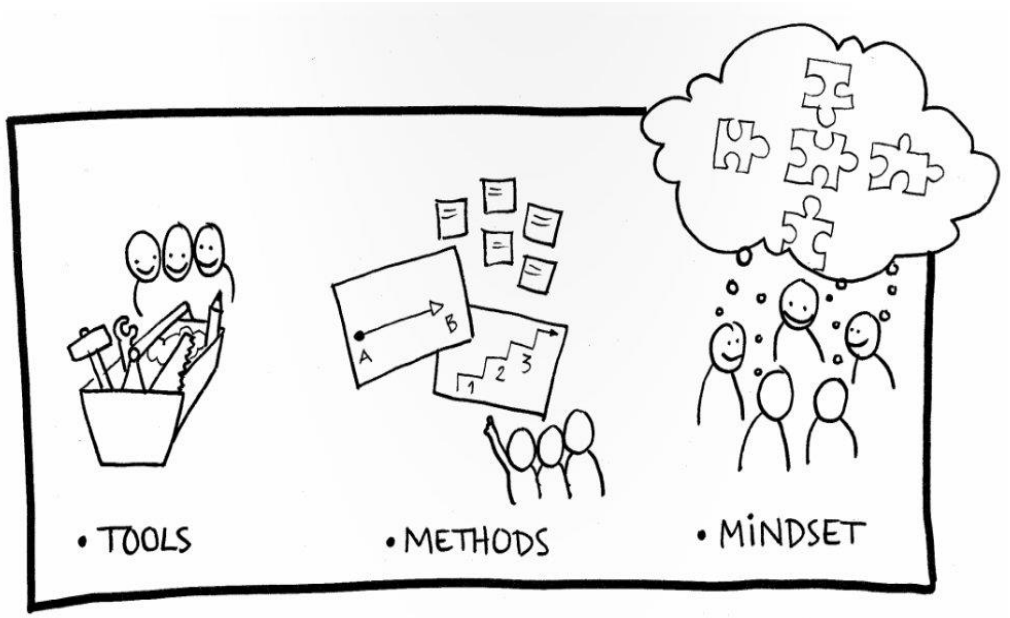
Use of Narratives in Experience-Based Co-Design

Objectives

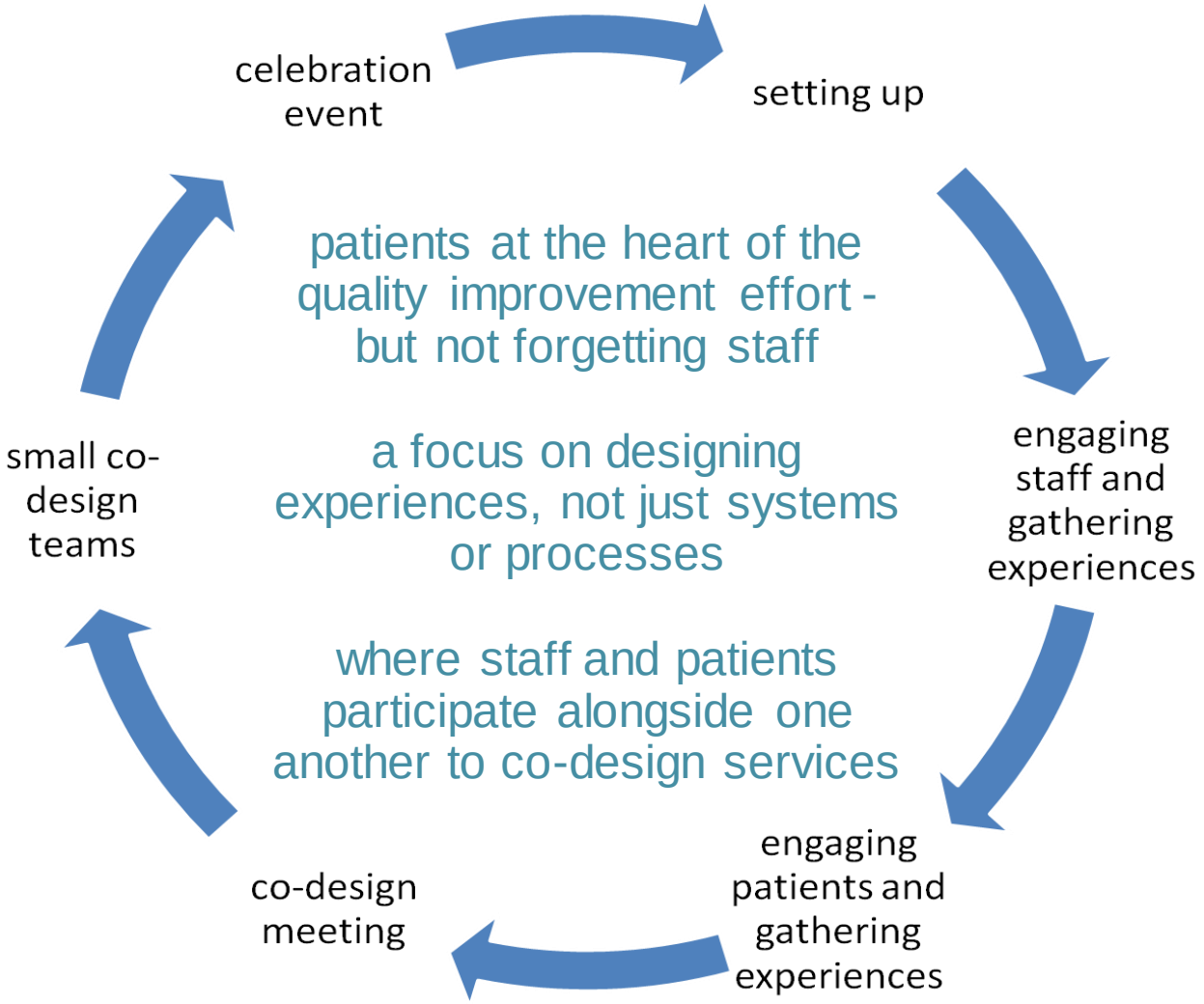
- Describe how patient and staff narratives have been used to drive improvement in Experience Based Co-design
- Explore how the challenges presented by COVID have impacted on the Experience Based Co-design methodology
- Describe how Experience Based Co-design can be adapted to include seldom heard groups.

Experience Based Co-Design in a nutshell – what is it and what does it achieve?

- A participatory action research approach that combines:
  a user-centred orientation (experienced-based) and
  a collaborative change process (co-design)
- Identifying key 'touch points' for both staff and patients throughout the experience of care
- Using experiences to identify improvement priorities, and devise and implement changes
- BUT also
- Changes mindsets
- Creates shared perspectives
- Includes patient and staff experience
- Represents a radical reconfiguration of power



The Experience-based Co-design process



Analysis of "touchpoints" – emotional or cognitive hotspots, things that stay with people for years afterwards.

Emotive / stand out phrasing often make them easier to spot

VON and Point of Care Foundation EBCD Work

Beth Israel Deaconess Medical Center Boston, MA

Randall Children's Hospital Portland,

Overland Park Regional Medical Center Overland Park, KS

Providence Portland Medical Center Portland, OR

Salem Hospital Salem, OR

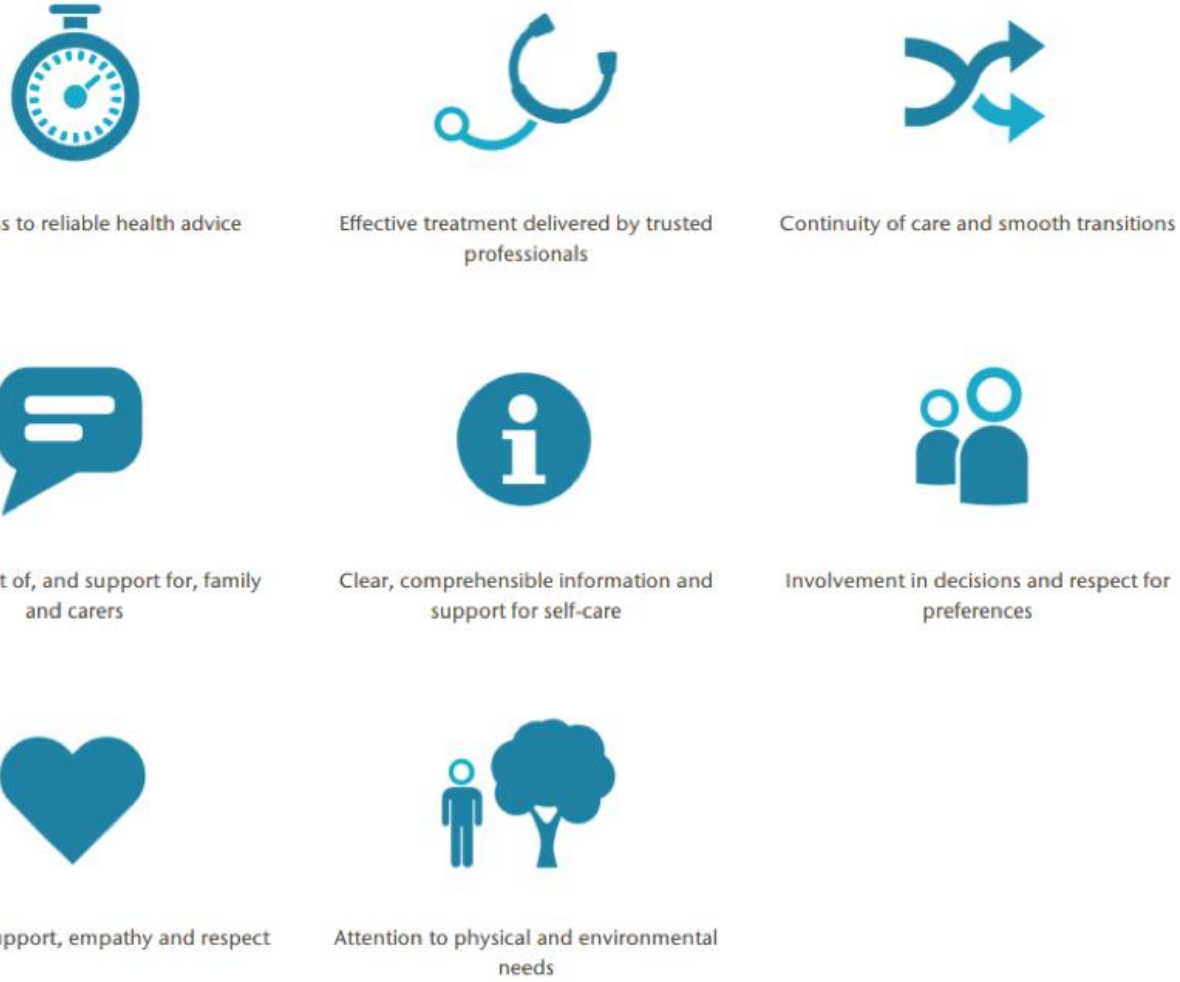
Use of health experience narratives

HSRU

- Done well, qualitative research can elicit rich accounts and deeper understanding of what matters to patients and families
- Analysis of *collections of narratives* can help us:
  - Learn more about what happens along the patient pathway (rather than what we think happens)
  - See things through patients' eyes
  - Rethink attitudes, redesign services

Source Professor Louise Locock

The process of the analysis phase
Identification of themes



Picker Institute

The collection and analysis of narratives – themes in NICU

- **Fear and the sense of being overwhelmed**

  What just happened ? Did I just have a baby upstairs?"

  "I'm sure she told me, but I wasn't really processing it…"

  "I didn't feel like I had had a baby until I held him"

- **Readiness for discharge and discharge itself**

  "There shouldn't have been so many doctors at the same time. It was so confusing"

- **The importance of relationships with staff**

  "I felt they (staff) had just as much skin in the game as I had"

  "I noticed the parent was at the side, not really being paid attention to…."

  "Kerry and Marcella taught me how to be a mother"

Filmed interviews

Interviews as data

versus

Interviews as connection and catharsis

The film is an important catalyst in the co-design process as the visualisation of patient experiences helps (re)connect people with similar experiences, whether users or providers of a service, and offers an emotionally and cognitively powerful starting point for the co-design process.

The visual medium sets the process apart from other consultative formats in which anonymity and circumspection can hinder rather than enable quality improvement.

Source: Donetto S et al 2014. Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions. London, National Nursing Research Unit, King's College London.

Can patient-researchers analyse narratives?

Yes …. But is the best use of their time?

- There is an academic debate about this
- Is it overwhelming them?
- Trying to turn patients into researchers versus
- Using their insights to guide the analysis
- Locock et al have developed what they called analytic conversation
- It is not without controversy!

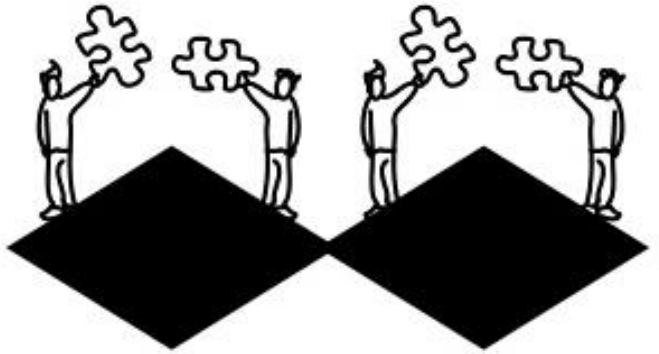
https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0133-z

What happens in the co-design phase?

- A joint ‘meeting’ to bring staff and patients together, to share themes and prioritise
- An opportunity for people to choose to belong to a co-design group and contribute to that work
- Taking the work forward in small co-design groups to come up with solutions and implement changes
- Examples of co-design groups
  - Physical layout
  - Communication with patients
  - Scheduling and appointments
  - Preparation for going home

The purpose of the co-design phase – its not just about data!

- To build a common understanding of what the care experience is like for staff and patients
- To agree that the common themes have been correctly identified
- To build trust so that staff and patients can work together as equals
- To prioritise the work to be taken forward
- As a motivator for action
- But materials from co-design can be used for education, induction, information giving and more.



Levelling up inequalities

- It's going to be a while before clinically vulnerable people are going to be able to come together in groups
- As with the analysis phase, there will need to be technological solutions to put on co-design events
- These changes can be democratizing – people who might otherwise find it difficult to attend, may find a technical solution / shorter meetings preferable
- It is likely to be less costly for the project team
- But it needs careful facilitation and inclusion – and the option for people to contribute in a variety of ways

So what needs to be done differently?

The principals are the same as for any good patient involvement strategy

- **Even more important that the "co" in "co-design" is meaningful**
- This means establishing **longer term relationships** with a group of patients / carers – so there is good understanding of what you are doing, and trust and rapport between contributors
- Start early, communicate often
- Make the purpose and scope clear
- Give people a good experience of contributing

Enabling access

- Offer familiarization sessions if people are not used to the technology
- Smaller groups can be less daunting
- Remote working offers the possibility of broader involvement – different times of day, no travelling etc
- Remote working offers the possibility of recording the event easily
- Be flexible about method – phone, documents to annotate etc as well as the meeting
- Use what the technology offers – jamboards for sticky notes, padlet, online polls…..

Example: families add their annotations and return

- Frightening, confusing
- We didn't know what was going on
- They were very kind, couldn't fault them
- Lovely
- I didn't like that each person did things differently
- It was all done in a RUSH!
- No support

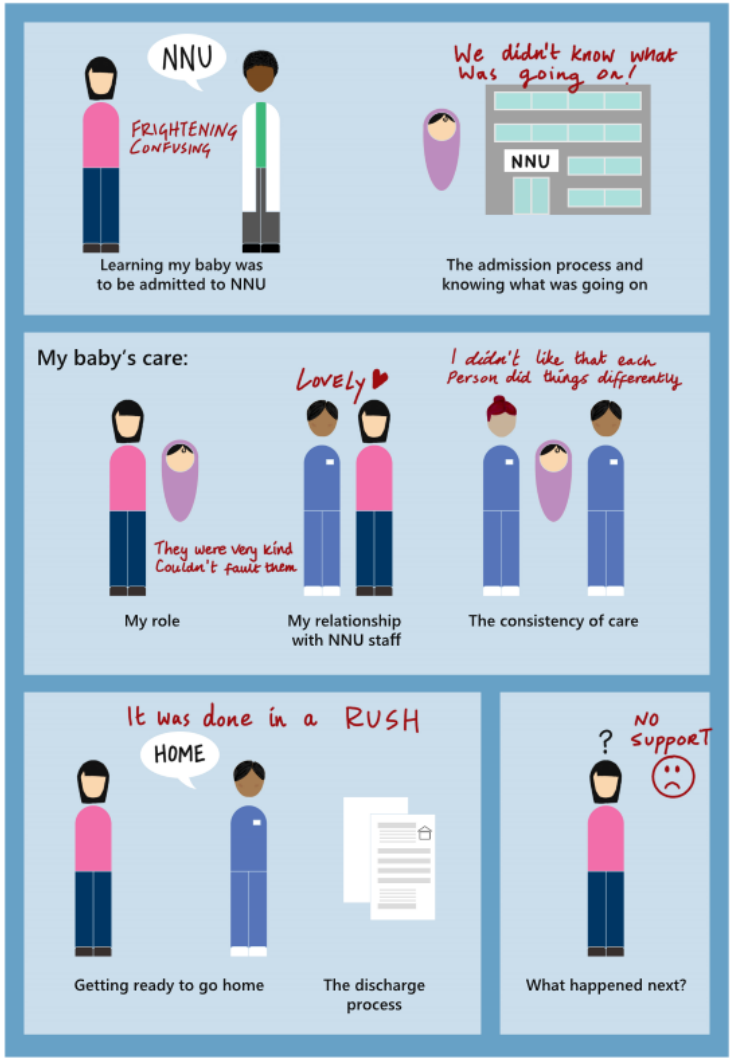
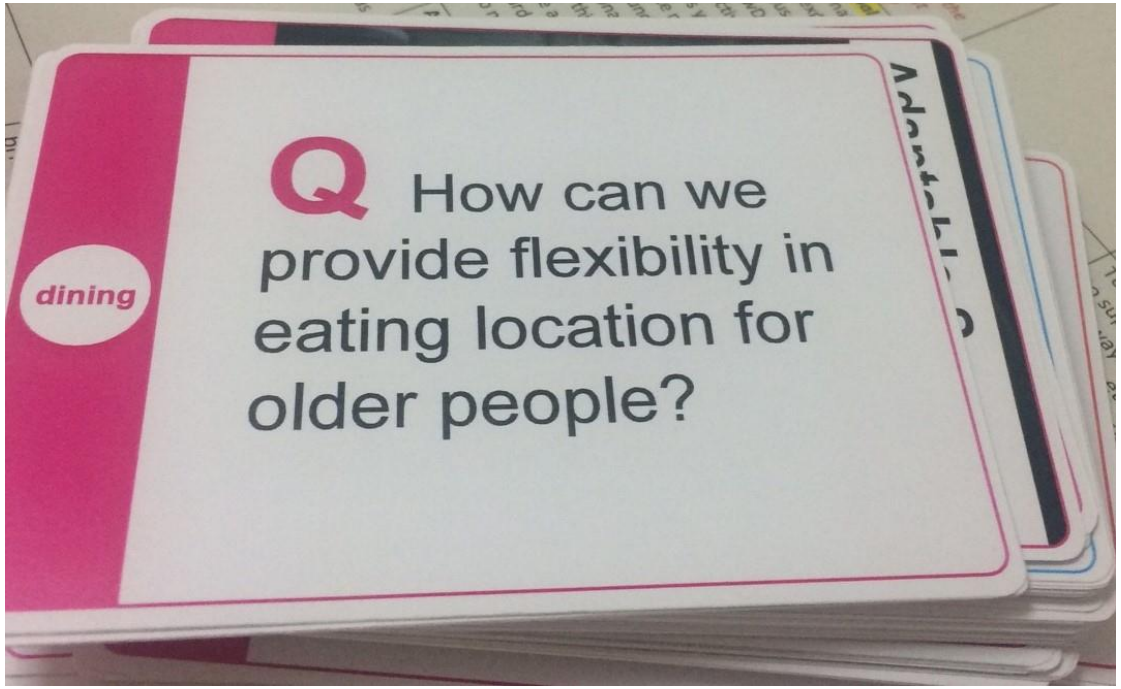


Image created by LizSappArt

OR provide an answer sheet for fuller responses



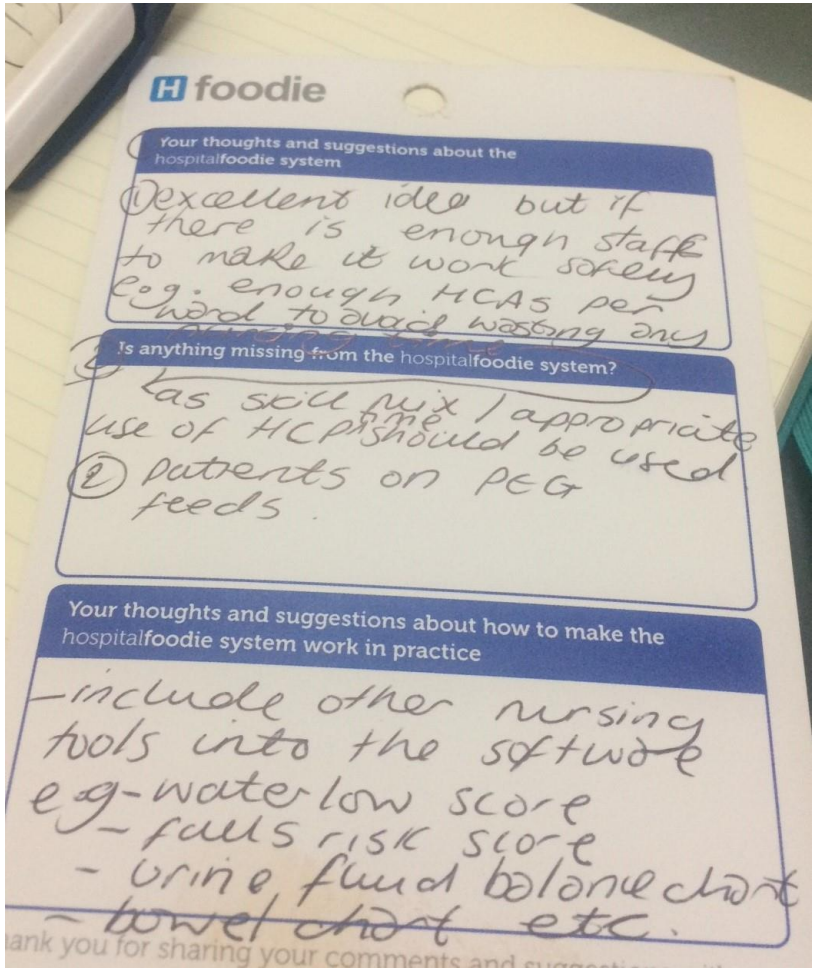


Image created by A McDonald – Glasgow School of Art

Connecting with staff values

> So I can see that this person is not only a human being, but he is also a father, he is a son, he is a brother, he is a friend, he is a cousin, he's a plumber or an electrician, he is a sportsman, he has an interest in horse riding, whatever it happens to be. He has a dog, he has a budgie, he has plans, he has expectations, he has regrets, he has feelings…

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