



*Patient involvement is everyone's responsibility – but how?
Using Q as an example*

International Forum on Quality and Safety in Healthcare

Session handout

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🐦 @theQcommunity or #Qcommunity

Sibylle Erdmann



Sibylle Erdmann is Chair of the London Neonatal Parent Advisory Board and a founding member of Q. She is currently undertaking a professional doctorate in organisational change, writing about health care decisions for children. Sibylle spent 400 days in hospital with her older son, who was born at 24 weeks. Her younger son has Cerebral Palsy, for which he receives specialist treatment.

In her work representing carers and patients, Sibylle combines her insights gained from lived experience with her doctorate research. She is an organisational psychologist by profession, having worked for 15 years with topics such as employee engagement within and outside of the UK.

Dominique Allwood



Dominique is a Senior Improvement Fellow at the Heath Foundation working on Q. She also works part time in NHS organisations supporting quality improvement and more effective involvement of patients and the public in health, care and improvement.

Dominique has been working as a doctor in the NHS for 14 years and qualified as Consultant in Public Health Medicine. She is passionate about involving patients, carers and the public in all aspects of health and health care and her other interests include population health, quality improvement and clinical leadership and development. Dominique was named one of HSJ's Rising Stars in 2015.

 *@DrDominiqueAllw*

Overview of Q

Q is an initiative connecting people, who have improvement expertise, across the UK. It is led by the Health Foundation and supported and co-funded by NHS Improvement.

Q's mission is to foster continuous and sustainable improvement in health and care. We're creating opportunities for people to come together as an improvement community – sharing ideas, enhancing skills and collaborating to make health and care better.

We are creating Q for the long term to support individuals and their existing improvement work, to benefit members' organisations and the populations they serve. It is designed to complement and help connect other improvement initiatives and networks.

The community is made up of a diverse range of people including those at the front line of health and social care, patient leaders, managers, researchers, commissioners, policymakers and others. This boosts the power of Q as a source of innovation and practical problem solving by including a wide range of perspectives.

The community is growing – over the coming years we envisage Q will become a community of thousands of people. We are supporting members to connect, collaborate, learn and exchange.

For more information about Q visit stand 12.

Co-designing Q – the early phase

To ensure Q met the needs of those in improvement, we worked together with a founding cohort of 231 people from 192 organisations to help design and test Q during 2015. We believe the process to design Q is the largest collaborative design process of its type undertaken in improvement in health care.

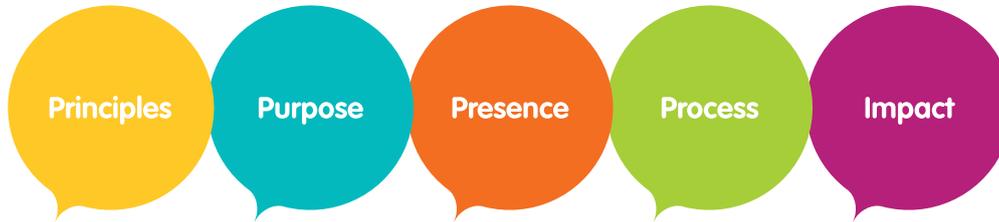
We sought to attract patients with experience and understanding of improvement to join the founding cohort of Q. A relatively small number of the founding members (nine members or 3%) defined themselves principally as patient leaders whose primary role or focus was bringing improvement experience from a patient or carer perspective. However, from our member evaluation survey we found that 32% of the founding cohort defined themselves as bringing a perspective as a patient and carer or acting within an organisation that represents patient and public perspectives.*

Working with these nine members and other members passionate about patient involvement, we created a small group. We explored themes around:

- the purpose of involvement
- the benefits to patient members, other members and the initiative overall
- the definition of a patient leader and other descriptors
- what level of improvement experience we might be seeking
- the different roles and types of involvement
- how to find and attract other patients with improvement experience.

*O'Malley H, Pereira P. *Building Q*. London: The Health Foundation, 2016. Available via q.health.org.uk/wp-content/uploads/2016/10/building-q.pdf (last accessed 21 April 2017) – refer page 31

4pi National Involvement Standards



Various models, frameworks and debates have informed our thinking. One of these frameworks is the National Involvement Partnership 4PI National Involvement Standards. In this presentation we aim to demonstrate how we applied the 4Pi framework* to help us inform our approach to involving patients in Q during and since the co-design period.

*The NSUN National Involvement Partnership Team *Involvement for Influence*. National Survivor User Network. 2015, Available via www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsFullReport20152.pdf (last accessed 21 April 2017)

PURPOSE

*Purpose &
belonging*

*Empower &
support*

*Unique insight
& perspective*

*Involvement
at all levels*

*Be the change
you wish to see*

PRINCIPLES PROCESS

How can we do this meaningfully

‘We want to develop a new level of collaboration between those involved in leading improvement, equally valued, regardless of their formal relationship to the health and care system’

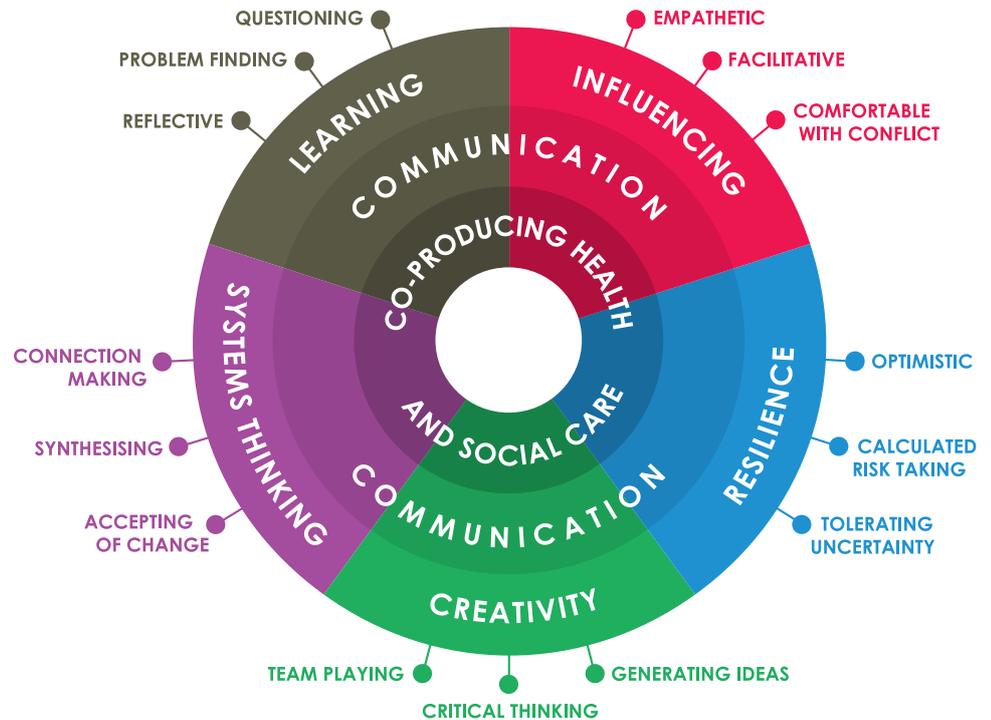
***Same selection
criteria***

***Different ways of
attracting people***

***Developing policy
for recognising
& remunerating
time & expenses***

PRESENCE

What habits of an improver do patients bring into this community?



Taken from *The habits of an improver*, the Health Foundation, 2015.
Download or order your copy at www.health.org.uk/publication/habits-improver

A purple speech bubble with a white outline and a small tail pointing towards the bottom-left. The word "Impact" is written in white, bold, sans-serif font in the center of the bubble.

Impact

As a member of the Q community

How do
I get in?

Where do
I belong?

What can
I do here?

How do
others
respond?

What is my
contribution?

Sharing some of our learning

Since the co-design process we have been recruiting new members. We have attracted more patients and carers with improvement expertise and now have more than 40 patient leader members in Q.* We are also bringing some of our learning about involving patients into other areas of Q including developing Q labs.

Our focus on attracting patients and carers to become members has raised some important questions and debate, such as whether there is a right number to be involved, and highlighted issues beyond Q. For example, it was quite challenging to identify patients and carers who had skills and experience in improvement – this may be partly due to relatively small numbers being involved in improvement and partly for other reasons such as how attractive Q was to them and the channels used to advertise opportunities.

* Based on information provided in applications (2015–17). Patient leaders includes those who classify themselves in their primary role as patient leader, service user, carer or expert by experience.

** Rand Europe. *An evaluation of the design phase of Q*. 2016. Available via: www.rand.org/t/rr1517 (last accessed 21 April 2017)

We found that members of Q who define themselves primarily as a patient or carer, or not formally employed in health or care, and are involved in improvement from this perspective see themselves differently to those who have experience of being a patient or carer who are formally employed in another role in health care. This was an important distinction.

Overall, Q members quoted time as the single biggest practical barrier to doing more improvement work. Improvement activities often seem reliant on discretionary effort (RAND survey).** For a lot of patients and carers involved in improvement, this is typically amplified as they are not employed, not embedded in a health care structure, with no regular pay or coverage of related expenses. We gained a lot of learning about this during the design process.

Key points

Other important points identified from some of our collective learning on patient involvement are:

- Ensure practical considerations are addressed: for example remuneration and requirements for accessibility. Be clear on what type of involvement you would pay for (time vs. expenses) so people are not out of pocket.
- Be mindful how patients are represented: as genuine co-producer and not tokenistic.
- Create effective platforms for exchange that are conducive to deeper listening: for example, by hosting smaller discussion or working groups around particular topics where patient perspectives can be heard.
- Model an inclusive network culture: pay attention to jargon language and avoid dismissive commentary (and discourage it if it arises from colleagues).

Frameworks and reading we found useful

There are different frameworks, theories and models of patient engagement and involvement and our thinking on involving patients in Q has been informed by a range of these. You may wish draw on a combination of several different sources for your work. We have listed some of these at the end of this handout.

We have referred to our use of the 4Pi framework in this presentation (there is a more detailed version on the next page), however there are others you may wish to look at such as the Coalition for Collaborative Care's Co-Production model.

4pi National Involvement Standards

4Pi is a framework for the involvement of service users and carers - in our own care, in our communities, in service delivery and evaluation and in organisational governance and strategy.

- 4Pi is a simple framework on which to base standards for good practice, and to monitor and evaluate involvement.
- The framework builds on the work of many people: mental health service users and carers and others who have lived and breathed involvement and shared their experiences in various ways, both written and unwritten.
- Meaningful involvement means making a difference: it should improve services and improve the mental health, wellbeing and recovery of everyone experiencing mental distress.



Principles

How do we relate to each other?
Principles and values are the rules or beliefs that influence the way we behave, the choices we make and the way we relate to other people.

Purpose

Why are we involving people?
Why are we becoming involved?

Presence

Who is involved?
Are the right people involved in the right places?

Process

How are people involved?
How do people feel about the involvement process?

Impact

What difference does involvement make?
How can we tell that we have made a difference?

A Co-production Model

Five values and seven steps to make this happen in reality

What is co-production?

Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective. Co-production is part of a range of approaches that includes citizen involvement, participation, engagement and consultation. It is a cornerstone of self-care, of person-centred care and of health-coaching approaches.

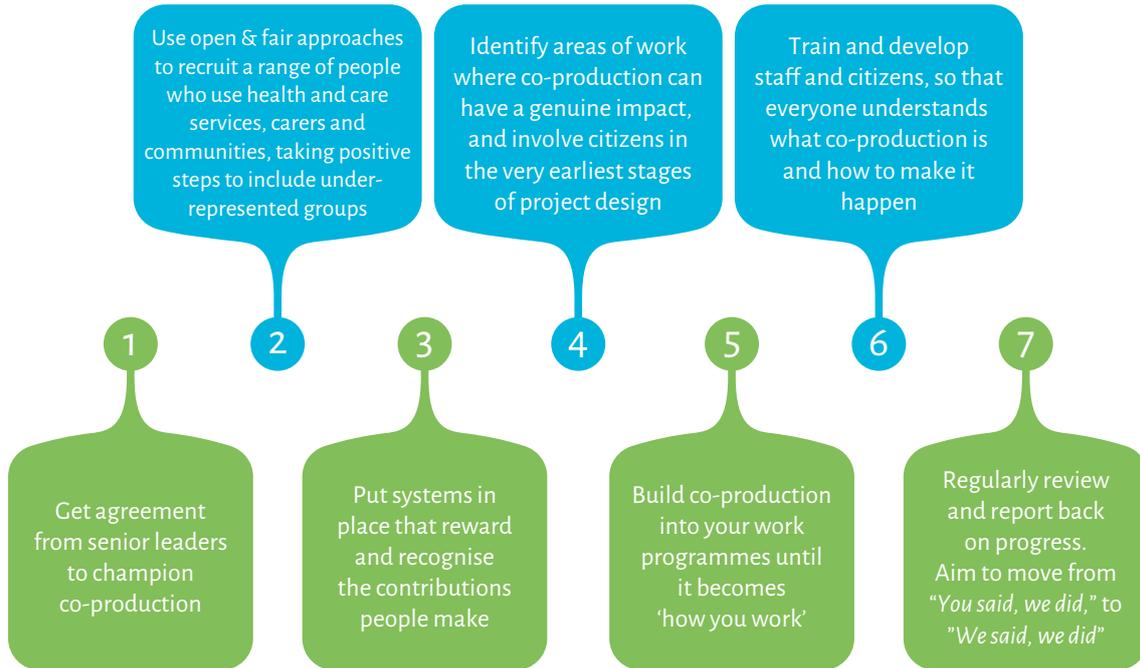
Values and behaviours

For co-production to become part of the way we work, we will create a culture where the following values and behaviours are the norm:



How to do it?

Seven practical steps to make co-production happen in reality:



Other references

Other sources of information and research
(all available at the Q stand – stand 12)

The NSUN National Involvement Partnership Team. *4Pi National Involvement Standards*. Available via <http://www.nsun.org.uk/about-us/our-work/national-involvement-partnership/national-involvement-standards-launched/>

The Coalition for Collaborative Care. Co-Production Model. Available via coalitionforcollaborativecare.org.uk/a-co-production-model/

Ocloo J, Matthews R. *From tokenism to empowerment: progressing patient and public involvement in healthcare improvement*. 2016. Available via <http://qualitysafety.bmj.com/content/25/8/626>

Batalden M, Batalden P, Margolis P, et al. *Coproduction of healthcare service*. 2015. Available via qualitysafety.bmj.com/content/25/7/509

O'Malley H, Pereira P. *Building Q*. London: The Health Foundation, 2016. Available via q.health.org.uk/wp-content/uploads/2016/10/building-q.pdf

Rand Europe. *An evaluation of the design phase of Q*. 2016. Available via www.rand.org/t/rr1517

The Health Foundation. *Leading Networks in healthcare*. 2013. Available via www.health.org.uk/publication/leading-networks-healthcare

Lucas B, Nacer H. *The habits of an improver*. 2015. Available via <http://www.health.org.uk/publication/habits-improver>

For more information, please visit our website at **q.health.org.uk** or call in at **stand 12** today.

You can also contact us by email at **q@health.org.uk**.

You can join the conversation via Twitter using **@theQcommunity** or **#Qcommunity**.

If you are interested in joining Q, please register for updates via the website.