MICROMASTERY OF PATIENTS & STAFF AS CO-DESIGNERS OF HEALTHCARE SERVICES

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A question from the back of the room:

“How many PDSA cycles did you complete?”
Where I thought I was in 2008
Where I actually was in 2008*
Where I am in 2018

Mastery is in the reaching, not the arriving

* Henriks, 2008

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- Our journey with co-design and co-production; the science and the practice
- Co-design and healthcare quality improvement
- Now the bad news ...
- State of the science: three Experience-based Co-design case studies
- A recap looking back on the last 13 years
Our journey with co-design and co-production; the science and the practice
Co-design and co-production: back to the 1970s

Co-design or co-production?

Co-designing a service involves sharing decision-making power with people. This means that people’s voices must be heard, valued, debated and then – most importantly – acted upon. Co-production goes one step further by enabling people to play roles in delivering the services that they have designed.

What has this got to do with improving quality in 2018?

“The more patients and families become empowered, shaping their care, the better that care becomes, and the lower the costs. Clinicians, and those who train them, should learn how to ask less, ‘What is the matter with you?’ and more, ‘What matters to you?’ Coproduction, co-design and person-centred care are among the new watchwords, and professionals, and those who train them, should master those ideas and embrace the transfer of control over people’s lives to the people.”

Where it all began (for us): design theory

- Draws its inspiration from a subfield of the design sciences such as architecture and software engineering.
- Distinctive features are:
  - direct user and provider participation in a face-to-face collaborative venture to co-design services, and
  - a focus on designing experiences as opposed to systems or processes (thereby requiring ethnographic methods such as narrative-based approaches and in-depth observation).

Design theory tries to describe or explain design activity.

Design theory

Performance

- Is it functional?
- Lean

Engineering

- Is it safe and reliable?
- Safer Patients Initiative

The Aesthetics of Experience

- What does it feel like?
- Physical environment
- Human environment
- Co-design

Source:
Berkun, S. (2004). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. Quality and Safety in Health Care, 13(5), 441-447.
13 years ago in a head & neck cancer service ...

A participatory action research approach that combines: a user-centred orientation (EB) and a collaborative change process (CD)
Co-design and healthcare quality improvement

- value in integrating human-centred tools and values of co-design into quality improvement approaches in healthcare organisations

- a co-design approach (Experience-based Co-design) as applied to quality improvement ‘work’ in healthcare services
Experience-based Co-design (EBCD)

https://www.pointofcarefoundation.org.uk/resources/experience-based-co-design-toolkit/


Staff wellbeing & patient experience

http://www.aprilstrategy.com/infographic/
Patient narratives and touchpoints

• Critical points
• Big moments (good and bad)
• Moments of truth
• Emotional hotspots
The co-design teams

CREATE NEWSLETTER
Collaborative Rehabilitation Environments in Acute Stroke

THE CO-DESIGN GROUPS

The co-design teams are facilitated by the development of changes and the engagement of the environment. The co-design teams are made up of healthcare professionals, family members, and stroke survivors. The co-design teams are key to the success of the project and are essential for the implementation of the research findings.

Practicalities

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SPACE

COMMUNICATION AND CULTURE

ACTIVITY COORDINATION

What counts as activity coordination? Activity coordination refers to the various ways to help people engage in physical and social activities.

What is the group’s purpose? Exploring how activities can be facilitated and how people can improve the patients’ discharge and functional health.

What are the ideas from the joint event? 1. Bring activities to the patients. 2. Involve friends and families. 3. Good idea. 4. Special emphasis on activities on the weekends. 5. Liaise with outside agencies.

A dedicated ‘activity lead’ role. How to act on emergent ideas in the group, you may think about “things that can be done now,” and “things that need more time,” planning your ideas down to action points. You may then think about ways to communicate your action points to the (follow) ward staff.
Prototyping

• move beyond talking and thinking about a touchpoint to actually making progress toward action
• giving permission to explore new behaviours
• lots of different methods: can vary from paper sketches, to a physical model, to a fully acted out service (role play)
• make prototypes ‘early, ugly & often‘; create something quickly, test it, and then iterate the design
• build buy-in from partners and other stakeholders
The Experience-based Co-design process

• TOOLS
• METHODS
• MINDSET

As a local QI intervention

• Improving the experiences of palliative care for older people, their carers and staff in the Emergency Department using EBCD
• Understanding Patient & Staff Experience of EBCD on an Acute Mental Health Ward To Promote Patient Centred Service Improvement
• Enhancing Therapeutic Engagement in Acute Psychiatric Wards: an EBCD project
• Safe management of people with Type 1 diabetes and EATing Disorder StudY (STEADY)

As part of MRC Complex Interventions framework

Enhancing the experience of carers in the chemotherapy outpatient setting: an exploratory randomised controlled trial to test impact, acceptability and feasibility of a complex intervention co-designed by carers and staff

As funded research

Doctoral/post-doctoral studies
Now the bad news ...

- Co-planning
- Co-management
- Co-assessment
- Co-innovation
"It's a magic potion that makes everything you say interesting."

Steve 'Doc' Baty
@docbaty

The phrase 'design thinking' is increasingly a sign-post to neither of those things.

11:27 AM - 5 Jul 2015

7 Retweets 14 Likes
The evidence base for co-design & co-production

• very weak on evidence of impacts

• breadth of terms & lack of focus; as meanings become more diffuse and confused, claims made for potential become more fanciful

• lots of single case studies (‘000s); strong on nature and level of co-design/co-production but weak on wider, long term impacts

• hope that can transform service outcomes without increasing costs unproven; economic case hard to sustain

• lack of longitudinal evaluation

Critiques of co-design, co-production

• little critical engagement with issues of power and power relations

• notions of equality, equal contribution & mutual respect are difficult to establish in health & social care

• service user empowerment & democratization of service provision risk being deployed simplistically

• ‘dark side’ (oppression & social exclusion):
  – reinforcing inequalities
  – ‘captured’ co-production
  – substitution of labour; socio-economic context in which co-production takes place (‘race to the bottom at time of austerity’)
  – cover for political decisions; constrained by ‘politically defined visions of the future’ or radically emancipatory in nature?
State of the ‘science’: three Experience-based Co-design case studies

Three EBCD case studies

• ‘My care, my voice’ in a learning disabilities service in Leicester, England

• ‘Accelerated’ EBCD in Intensive Care Units and lung cancer services in Reading & London, England

• People living with severe mental illness in Victoria, Australia improve psychosocial recovery outcomes (CORE)
‘My care, my voice’ in a learning disabilities service
Humanising healthcare

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‘Accelerated’ EBCD: improvement activities & trigger films

- similar improvement activities to standard EBCD projects
- 48 improvement activities in total:
  - 21 small scale changes
  - 21 process redesign within teams
  - 5 process redesign between services/activities
  - 1 process redesign between organisations
- costs of AEBCD are around 40% of EBCD (excluding one-off costs of developing a national trigger film)


http://www.healthtalk.org/peoples-experiences/improving-health-care/trigger-films-service-improvement/topics
Getting to the CORE: testing a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness

A theory of change ...

Appendix 5: A program logic model for the CORE study: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness.
Eight proposed mechanisms of change

A recap looking back on the last 13 years
Where has co-design reached?

- lower levels of involvement in latter co-design process; patients feel that technical dimensions of implementing QI solutions lie with staff?
- further (creative) work is needed to overcome tendency towards administrative & bureaucratic processes
- emotional work: requires ongoing support to ensure patients can play a meaningful role as co-designers in QI
- interpersonal burden for patients, carers and staff in speaking across socio-cultural and organizational boundaries
- facilitation role is critical

Recap

- neither co-design nor co-production are new concepts
- situating them within healthcare ‘Improvement Science’ is (relatively) new
- misuse of terms & concepts risks denuding them of radical meaning
- focus needs to shift away from collecting more data on patient experience towards embedding co-design/co-production mindset as a way of doing QI ‘work’ in healthcare
- evidence is growing about the effectiveness of co-design/co-production approaches but what are our theories of change?
- co-design/co-production represent a radical way of thinking of the role of patients & a structured process for involving them in all stages of QI
Further information

• EBCD toolkit: https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/

• EBCD LinkedIn group: www.linkedin.com/groups/Experiencebased-codesign-6546554

• Twitter: @gbrgsy, @PointofCareFdn

• EBCD one day training course, team email: info@pocf.org.uk

• Glenn Robert email: glenn.robert@kcl.ac.uk