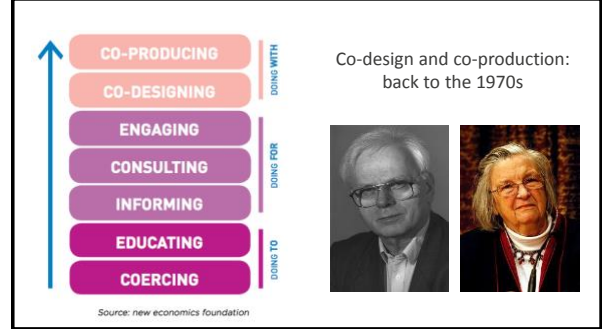# PATIENTS & STAFF AS CO-DESIGNERS OF HEALTHCARE SERVICES: CO-CREATING PATIENT EXPERIENCES & STAFF WELLBEING

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Co-design and co-production: back to the 1970s

Source: new economics foundation

What is Co-Design?

- co-design is a well-established approach to creative practice
- enables a wide range of people to make a creative contribution in the formulation and solution of a problem
- builds and deepens equal collaboration between citizens affected by, or attempting to, resolve a particular challenge; users, as 'experts' of their own experience, become central to the design process
- enables people to engage with each other as well as providing ways to communicate, be creative, share insights and test out new ideas
- wide range of tools/techniques support co-design process: user personas, storyboards, user journeys, prototyping and scenario generation techniques

Source: John Chisholm, 'What is Co-Design?' http://designforeurope.eu/what-co-design (accessed March 2016)

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
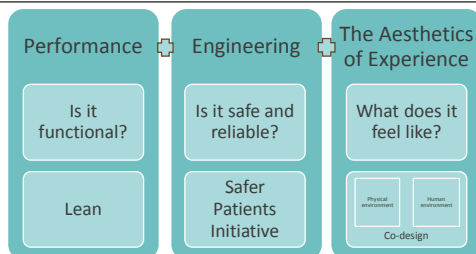
Bate p., 2004 adapted by Bate. Source: Bate P, Robert G (2006) 'Experience-based design. From redesigning the system around the patient to co-designing services with the patient.' Quality and Safety in Health Care vol 15 (5), pp 307–10

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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 & healthcare quality improvement

- value in integrating human-centred tools and values of co-design into quality improvement approaches in healthcare organisations
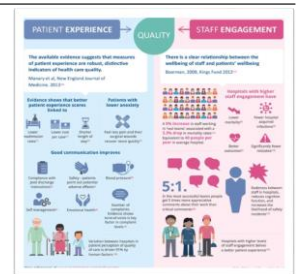
- a co-design approach (Experience-based Co-design) as applied to quality improvement 'work' in healthcare services

Staff wellbeing & patient experience

Patient narratives and touchpoints

- Critical points

- Big moments (good and bad)

- Moments of truth

- Emotional hotspots

## A touchpoint: the radiotherapy planning meeting …
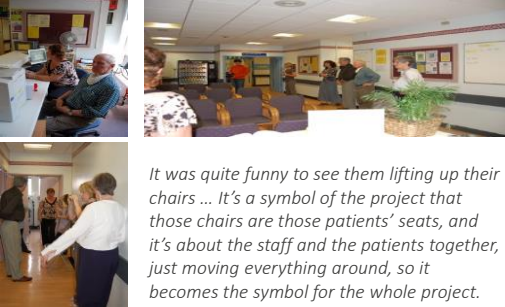
The co-design teams

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
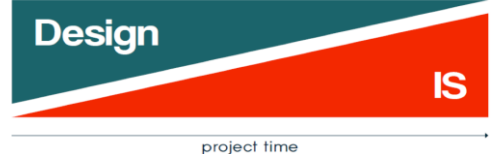- build buy-in from partners and other stakeholders
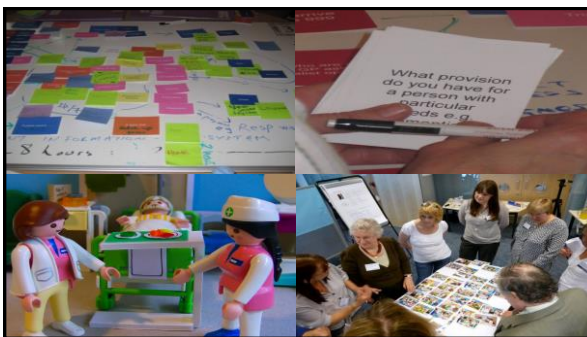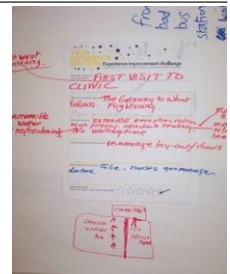
The Experience-based Co-design **process**

- TOOLS
- METHODS
- MINDSET
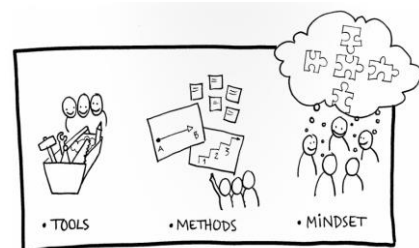
It was quite funny to see them lifting up their chairs … It's a symbol of the project that those chairs are those patients' seats, and it's about the staff and the patients together, just moving everything around, so it becomes the symbol for the whole project.

Emphasis

project time

'Design vs Implementation Science for systems change', 21/11/2016, https://unpackingsocialdesign.wordpress.com/2016/11/21/2-1-design-vs-implementation-science-for-systems-change/

As a local QI intervention

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
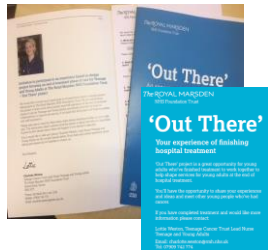
Doctoral/post-doctoral studies

- 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)

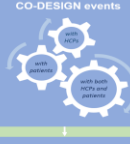### As funded research

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'Out There': Developing a transition pathway for adolescent & young adults (AYA) with cancer

- using EBCD in AYA oncology setting to develop a transition pathway from hospital to home following treatment
- video recording of interviews for both staff & AYA in order to give each group equal experience of engagement in EBCD process
- mobile phones for clinical nurse specialists to use to communicate with AYA patients
- support with fertility and relationship advice at key points during and after treatment

Lottie Weston, Teenage Cancer Trust Lead Nurse – Teenage & Young Adults, The Royal Marsden NHS Foundation Trust, charlotte.weston@rmh.nhs.uk

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Chemotherapy-induced peripheral neuropathy: co-designing & feasibility testing a behavioural intervention to improve functional status & quality of life

Mary Tanay, Senior Teaching Fellow, King's College London, mary.tanay@kcl.ac.uk

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- Co-planning
- Co-management
- Co-assessment
- Co-innovation

"It's a magic potion that makes everything you say interesting."

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?
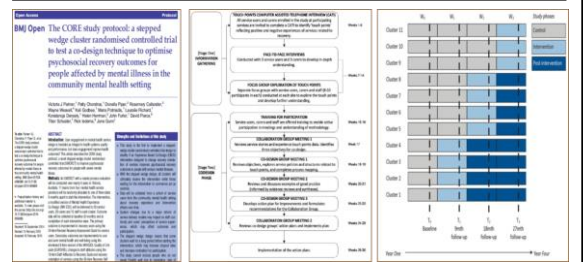
Iedema, R, et al. (2010). 'Codesigning as a Discursive Practice in Emergency Health Services: The Architecture of Deliberation'. *The Journal of Applied Behavioral Science*, 46: 73–91; Farr, M. (2013), 'Citizens and the co-creation of public service innovation'. In Osborne, S. P. and Brown, L. (eds), *Handbook of Innovation in Public Services*. Cheltenham: Edward Elgar, pp. 445–458 ; Osborne, S et al. (2016). Co-production and the co-creation of value in public services: a suitable case for treatment? Public Management Review, 18 (5), pp.639-653; Fotaki, M. (2015) Co-Production Under the Financial Crisis and Austerity . Journal of Management Inquiry, 24(4): 433 - 438 ; Loeffler E & Bovaird T. (2016) User and Community Co-Production of Public Services: What Does the Evidence Tell Us? International Journal of Public Administration, Vol. 39

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
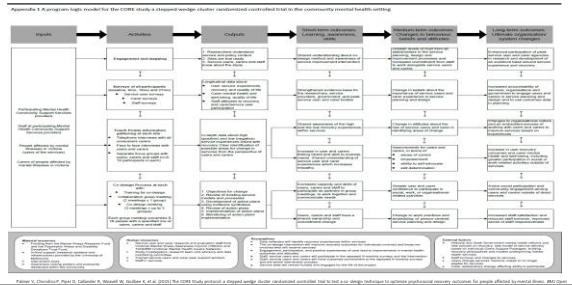
- lack of longitudinal evaluation

Loeffler E & Bovaird T. (2016) 'User and Community Co-Production of Public Services: What Does the Evidence Tell Us?' International Journal of Public Administration Vol. 39; Durose C, Needham C, Mangan C et al. (2017) Generating 'good enough' evidence for co-production. Evidence & Policy, 13(1): 135-151

Getting to the CORE: testing a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness

Palmer V, Chondros P, Piper D, Callander R, Weavell W, Godbee K, et al. (2015) The CORE Study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness. BMJ Open.

A theory of change …

Palmer V, Chondros P, Piper D, Callander R, Weavell W, Godbee K, et al. (2015) The CORE Study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness. BMJ Open.

'My care, my voice' in a learning disabilities service

Humanising healthcare

Forms of humanization	Forms of dehumanization
insiderness	objectivication
agency	passivity
uniqueness	homogenization
togetherness	isolation
sense-making	loss of meaning
personal journey	loss of personal journey
sense of place	dislocation
embodiement	reductionist body

Adapted from Todres L, Galvin T and Holloway I (2009) The humanisation of health care: a value framework for qualitative research. *Int J of Qualitative Studies on Health and Wellbeing*, 4: 68-77

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

Experience-based Co-design (EBCD)