Approaches and methodologies of patient co-production/design

A rapid review of existing evidence

December 2016
Charlotte Owen

NHS

Overview

"Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change." (http://www.nesta.org.uk/sites/default/files/co-production_catalogue.pdf pg 5)

Six elements have been outlined which are the foundation stones of co-production. What is immediately clear is how much these definitions overlap with each other. Co-production in practice will involve alignment with all of these features, and they are all underpinned by similar values (http://coproductionnetwork.com/page/about-coproduction):

1. **Building on people's existing capabilities**
2. **Reciprocity and mutuality**
3. **Peer support networks**
4. **Blurring distinctions between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered**
5. **Facilitating rather than delivering**. **Enabling public service agencies to become catalysts and facilitators rather than central providers themselves**
6. **Asset based and transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services**

The following slide lists the case studies and provides their key quantified impact. It is important to note that as this is a rapid review, it is not systematic nor does it cover all existing initiatives and data on the subject. Rather it pulls out some key examples to share learning and provide good practice guides.

Methodology
The rapid review used mixed methodology combining qualitative and quantitative approaches to capture a broad range of examples. The first stage used desktop research via academic resources such as the King's Fund, NESTA and Nuffield Trust. The research team also examined a range of sources such as project reports, stakeholder websites and press releases and then contacted project leads and practices directly to identify the quantifiable impact of the studies and fill in any missing information.

For more information please contact: natalia.proctor@nhs.net

Key studies and their impacts

Page	Study	Key Impact
5	Case Study 1: Oxleas NHS Mental Health Trust - Experience based co-design (EBCD) toolkit	*Improvements made to mental health inpatients that resulted in 80 per cent reduction in complaints within 14 months.*
6	Case Study 2: Partnerships for Older People Projects - NESTA co-production catalogue	*Increasing number of services available to support older people to stay well and out of hospital to improve quality of life and reduce demand on services.*
7	Case Study 3: Local Area Coordination - NESTA Co-production catalogue	*Support people with disabilities to live as part of their community and develop networks to help them in difficult times rather than waiting for crisis before intervening.*
8	Case Study 4: Personalised Integrated Care Programme AGE UK	*Working across a range of services to enable older people to remain active and independent as long as possible and support them reducing the need for emergency interventions/recurring hospital admissions.*
9	Case Study 5: Accelerated EBCD. Using a national archive of patient experience narratives to promote local patient-centered quality improvement: an ethnographic process evaluation of 'accelerated' experience-based co-design	*An accelerated approach to EBCD using videos created nationally to open opportunities for constructive discussion. A fast and cost-effective method of EBCD.*
10	Case Study 6: 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 in the community mental health setting	*No quantifiable impact found. However this study uses a novel stepped-wedge cluster approach, and it may prove interesting to look at the pros and cons of a different approach to the study.*
11	Appendix – Further Resources	*Not applicable*

Case Studies

Case Study 1: Oxleas NHS Mental Health Trust - (EBCD Tool kit)

Background:

In 2012, Senior management and staff in Oxleas NHS Mental Health Trust decided to make improvements to the ward after **initial approaches had been producing disappointing results**.

They wanted to find a way of closing the circle – asking for patient experiences and then delivering that information back in a way that led to positive, concrete changes.

The Approach:

- An experience-based co-design (EBCD) approach was used to make improvements to the mental health inpatient service.
- The toolkit captured the experiences of patients, carers and staff through discussion, observation and filmed interviews.
- Participants were recruited from ResearchNet, a pre-existing service-user group.
- The ResearchNet team co-managed the entire process, including filming, managing consent and running events, supported by NHS colleagues.
- Feedback from daily groups on the ward, based on the emotional touchpoints, was linked back to staff supervision and became part of the primary tasks of the ward.

Impact and outcomes

- The results were impressive, with complaints **reduced by 80 per cent** over 14 months.
- The initiative greatly improved patient experience as demonstrated by reduction in complaints, feeling of empowerment experienced by those involved in the study.
- The process also had a strong impact on staff and they changed their accelerated triage system to a model of care that was more aligned to service users' needs, as identified through EBCD.

Learning Points

➢ *Mental health inpatients are uniquely vulnerable within the EBCD process because of the unique features of these services, so it is essential to adapt the process in order to reassure and support them.*

➢ *Recruit patients from existing, well-established support groups or put that support in place.*

➢ *Allow plenty of time to build trust before you get started. Oxleas met with patients for six months before they felt it was appropriate to start EBCD.*

➢ *If handled correctly, positive outcomes may include fewer complaints, shorter inpatient stays, fewer readmissions and a sense of empowerment for patients who have taken part in the process.*

References: https://www.kingsfund.org.uk/projects/ebcd/case-study-1-running-ebcd-mental-health-inpatient-service

Case Study 2: Partnerships for Older People Projects - NESTA Co-production catalogue

Background:.

In 2006 the Department of Health set up the Partnership for Older People Projects (POPP) initiative to provide improved health and well-being for older people via a series of individual projects providing local services.

These services were to be person-centred and integrated, to promote health, well-being and independence, and to prevent or delay the need for higher intensity or institutional care.

There was an expectation that strong partnerships would be forged with local providers of health care, as well as with many other local organisations, particularly local voluntary and community organisations (VCOs). A greater involvement of older people themselves was also an objective of the initiative.

The Approach:

- The Department of Health designated 29 pilot sites in local authorities (19 in a first round and ten in a second round), running from May 2006 through March 2009.
- 146 core local services were established for people needing significant support, such as people (and their carers) with long-term conditions.
- A further 530 small 'upstream' projects commissioned from the third sector were described as low level preventative programmes and were open to all older people. Over 260,000 people used the services of POPPs over the three years.
- All local projects involved older people in their design and management, including as members of steering or programme boards, in staff recruitment panels, as volunteers or in the evaluation.

Impact and outcomes:

- For every extra £1 spent on the POPPs services, there was approximately a **£1.20 additional benefit in savings** on emergency bed days.
- Overnight hospital stays were reduced by **47 per cent**.
- Use of Accident and Emergency Departments reduced by **29 per cent.**
- Reductions were also seen in physiotherapy/occupational therapy and clinic or outpatient appointments with a total cost reduction of **£2,166 per person**.
- Evidence also showed that for users receiving 'well-being or emotional' interventions, a category that included befriending, fewer reported being depressed/anxious following the intervention: **58 per cent before and 63 per cent after the intervention**.
- Looking at quality of life improvements as a result of better mental health – using evidence from some of the POPPs pilots – their monetary value would be around **£300 per person per year**.
- The overwhelming majority of the POPPs have been sustained, with **only 3 per cent being closed** at the end of the pilot phase.

Case Study 3: Local Area Coordination - NESTA Co-production catalogue

Background:

Local Area Coordination (LAC) is an approach to supporting people with disabilities to live good lives in their communities. The model was first developed and implemented in Western Australia in 1988. Since then, reflecting its success, the approach has been adopted across Australasia, in Canada, Ireland, Scotland and England.

Rather than defining people by their needs and the services they use, LAC asks people what sort of lives they want to lead and then supports them to achieve their aspirations.

In doing so, the LAC approach helps promote individual strength and resilience, rather than waiting for a crisis before intervening.

The Approach:

- Local Area Coordinators act as single points of contact in a defined local area.
- Supporting between 50-60 individuals and their families in their local communities.
- The Coordinator's enable people to make the most of their skills and capabilities and the resources and assets within their community.
- If these capabilities, resources and assets are weak, the Coordinator will seek to develop them.
- The Coordinator builds and develops personal and community networks.
- These networks support people through difficult times, provide practical responses to their needs and help them to achieve their aspirations.

Impact and outcomes:

- Good value for money - evaluations of the LAC service in Australia have demonstrated a **30% reduction** in costs as part of a move towards a preventative service.
- **Lower levels of acute interventions** and much higher levels of participation and enthusiasm from the people who use the service.
- High levels of user satisfaction**.**
- Responsive and flexible service provision, the service has proven a strong ability to adapt with the changing needs of the service 'users'.
- LAC helps people to move away from seeing formal services as being the inevitable first port of call, by developing informal and more personal forms of support over which they have a much greater degree of control and ownership.

Reference: http://www.nesta.org.uk/sites/default/files/co-production_catalogue.pdf (case study 7)

Case Study 4: Personalised Integrated Care Programme AGE UK

Background:

There are too many older people with long-term conditions who are not getting the personalised, integrated care and support they need to live independent lives in their community.

Instead, all too often they are in and out of hospital with no sustainable plan to keep them fit and well.

The programme aims to support older people with long term health conditions to stay well and independent to avoid recurring hospital admissions and so reduce demand on services.

The Approach:

- Local voluntary and health & care organisations come together to put the older person in control of their health and enable them to regain their independence and quality of life.
- **Risk stratification** identifies a specific cohort of older people with multiple long-term conditions who are vulnerable to unplanned admission to hospital.
- Using a **'guided conversation'**, an Age UK Personal Independence Co-ordinator draws out the goals that the older person identifies as most important to them.
- Together, they create a **care plan** which brings together services from across the health, social care and voluntary sectors that are appropriate for the older person's need.
- Effectively, the services 'wrap around' the older person, with the aim of reversing the cycle of dependency.

Impact and outcomes:

Looking at the first 325 older people who went through the programme, the following has been observed:

- 31% reduction in all hospital admissions

- 26% reduction in non-elective hospital admissions

- 20% average improvement in wellbeing

- 20% of people supported go on to become volunteers themselves

- 8% reduction in social care costs

Case Study 5: Accelerated EBCD – an ethnographic process evaluation

Background:
This study evaluates an accelerated form of experience-based co-design (EBCD), using national patient experience films (instead of those created locally) to enable co-production. The study observed how acceleration of the EBCD method affected the process and outcomes of the intervention. It was tested in intensive care and lung cancer in two English NHS hospitals.

The Approach:
- Retaining all components of EBCD, the adapted approach replaced local patient interviews with secondary analysis of a national archive of patient experience narratives to create national trigger films.
- This shortened the timeframe.
- Local improvement facilitators were employed.

Impact and outcomes:
- The resulting 48 co-design (improvement) activities across the four pathways were similar to those in EBCD, but achieved **more quickly** and at **lower cost**.

- **Patient experience was improved** and patients felt empowered and that they had been listened to and treated as equals in the process.

- The research team believe this is an approach that can **revitalise staff**.

- The data suggest face-to-face encounters with patients in co-design groups often had a profound effect on staff in making them think differently about their practice and reconnect with their core professional values, resulting in **renewed motivation**.

Learning Points:
➤ Using films of national rather than local narratives did not adversely affect local NHS staff engagement, and may have made the process less threatening or challenging.
➤ While on occasion the result can be conflict and negative outcomes, the review demonstrates that partnership synergy brings many benefits including:

> ➤ culturally and logistically appropriate research;
> ➤ better quality of outputs and outcomes over time;
> ➤ increased sustainability of project goals beyond funded timeframes;
> ➤ system changes; and new, unanticipated projects and activities.

➤ This resonates strongly with the research findings, and is the antithesis of the problems underlying the Francis Report of failing to listen to patients or take their concerns seriously.

References: http://hsr.sagepub.com/content/19/4/200.full

Case Study 6: The CORE study protocol

Background:

User engagement in mental health service design is heralded as integral to health systems quality and performance, but does engagement improve health outcomes?

This article describes the CORE study protocol, a novel stepped wedge cluster randomised controlled trial (SWCRCT) to improve psychosocial recovery outcomes for people with severe mental illness.

The Approach:

- The stepped wedge design, means all clusters will ultimately receive the intervention while those waiting for the intervention to commence act as controls.
- 11 teams from four mental health service providers were randomly allocated to one of three dates 9 months apart to start the intervention, which takes place over nearly 4 years.
- The study team developed and implemented the model of engagement to underpin the trial. This seeks to:
  - build enduring relationships with all staff, service users and carers to last the length of the trial;
  - communicate trial requirements to staff to encourage stronger implementation and hence embedding of the intervention into the setting;
  - to keep service users and carers engaged during the wait periods for the intervention

Impact and outcomes:

- The longitudinal design offers a major strength for developing better insights into recovery outcomes over time for people affected by serious mental illness in the community mental health setting.
- This is ongoing research but the primary expected outcome is improvement in psychosocial recovery for individuals measured within 9 months from the beginning of each intervention wave.
- Secondary expected outcomes are changes to service users and carers' mental health and well-being and changes to staff attitudes to recovery and recovery orientation of services.

Learning Points:

- Delivery of the intervention can be staggered to manage the practical and logistical constraints that would come with the delivery of the intervention concurrently in 11 clusters.
- The staggered implementation of the intervention also allows for time effects to be taken into account on the outcome measures; this provides much greater depth of analysis than a pre-post design.
- However, the stepped wedge design means that some clusters wait for a long period before starting the intervention, which may increase dropout rates and decrease motivation for participation. The study team developed the engagement model to counteract this negative effect.

References: : https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4386225

Appendix
Further Resources

Further Resources

Title and Description	Link
How to involve and co-produce with patients and communities - Implementing the six principles - King's Fund event held in November 2016 that brought together national leaders and local innovations from across the country, and demonstrated examples of how to implement the six principles of co-production which set out the basis of good person-centred, community-focused care using the experiences of patients and organisations and sharing their learning.	https://www.kingsfund.org.uk/events/how-involve-and-co-produce-patients-and-communities
Experience Based Co-Design Toolkit - This toolkit outlines a powerful and proven way of improving patients' experience of services, and helps you to understand how it can help you meet your aims.	https://www.kingsfund.org.uk/projects/ebcd/case-study-1-running-ebcd-mental-health-inpatient-service
NESTA Co-Production Catalogue - The catalogue brings together inspiring examples of collaborative public services in action, with a particular focus on health and social care. The catalogue includes **20 case studies** with a variety of different impacts and outcomes across different services.	http://www.nesta.org.uk/sites/default/files/co-production_catalogue.pdf
Co-creating Health Programme - Aimed to embed self-management support within mainstream health services across the UK, Worked across eight sites between 2007-2012; Each site focused on one of four clinical areas: COPD, depression, diabetes and musculoskeletal pain.	http://www.health.org.uk/programmes/co-creating-health
Promoting Patient and Family Partnerships in Ambulatory Care Improvement: A Narrative Review and Focus Group Findings – Review of literature published from 2000–2015 and a focus group conducted in 2014 with practice advisors.	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969329
Co-designing pathways to support the transition from hospital to home - This project worked with health and social care practitioners, older people, their families and informal carers to identify and improve care pathways from hospital to home and enable a more positive experience for all during this transition.	http://www.coproductionscotland.org.uk/resources/resource-case-studies/from-hospital-to-home
Personalisation and Self-care Programme, Healthy London Partnership Website	https://www.myhealth.london.nhs.uk/healthy-london/programmes/personalisation