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# How co-production is used to improve the quality of services and people's experience of care: A literature review

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## Content



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## Questions to answer through the review

- What evidence is there about how co-production is used to improve the quality of services and people's experience of care?
- What makes co-production successful?
- What are the challenges and barriers in using co-production to impro quality of services and people's experience of care?

- How does co-production work in different settings/situations, and for different groups?

## The literature review process

## How the papers were selected

## Inclusion criteria

Co-production (and related terms) as the main intervention that clearly reflects the following elements/activities:

- Equal relationship/working between people with lived experience (service users and family/carers)
  and those with learnt experience (service providers, professionals).
- Services are designed, commissioned and/or delivered in equal partnership by all parties.
- Activities result in benefits enjoyed by whole communities, groups, and/or a service and not just individual/personal benefit only.
- Papers from 2008 - 2020.

## Exclusion criteria

Unclear understanding of what the paper means by co-production or related terms, or the terms used does not clearly reflect the inclusion criteria elements/activities – for example:

- The relationship between service users and providers is not equal.
- Activities undertaken by individuals for their own benefit (eg self care/management, improve own health, or improve own experience of care) and not whole service delivery or community/group's benefit.
- Co-produced research or evaluation of a service/intervention but the design, commissioning or delivery of the service/intervention is not co-produced.

## Numbers and types of papers gathered

## Inclusion criteria

Lots of interest in co-production and related concepts in both peer-reviewed and grey* literature

- 64 papers selected after full text reviewed:

    - 37 in UK
    - 11 in USA and Canada
    - 3 in Australia
    - 13 from other countries.
- Type of publication:
    - 10 grey* literature
    - 54 journal articles.
- Type of literature:
    - 8 case studies
    - 6 position/discussion papers
    - 3 literature reviews
    - 3 practical guidelines.
- Type of service:
    - 13 in multiple/mixed settings
    - 12 in acute care
    - 7 in mental health
    - 4 in primary care
    - 3 in paediatrics and maternity.

* 'Grey literature' refers to information produced outside of normal publishing and distribution channels, for example policy documents, internal documents, etc.

## The literature review summary

### Overview of available literature

Co-production is often used loosely to cover a range of related concepts, however, 6 core principles are common

1. There is no single, universal model of co-production and the way co-production is done varies in each situation depending on the task, context and the people involved,
2. Improved experience is consistently seen as a result of the co-production approach, alongside improved efficiency and improved clinical outcomes,
3. In many cases, service improvement based on patient experience is not often a priority, and the extent of integration of patient experiences in service improvement is often unclear,
4. Experience-based co-design (EBCD) and the Always Events® are the only two approaches to co-production that emphasise the systematic collection and use of patient experiences to improve healthcare services.
5. Common to both approaches is the identification of touchpoints based on participant's real experiences that are translated into service-specific improvement priorities.

6. The alignment of quality improvement and co-production is influenced by:
    - system level factors
    - organisation requirements
    - point of care requirements
    - valuing different forms of evidence.

## Defining co-production

## How co-production is described in the literature

Co-production is often used loosely in the literature to cover a range of related concepts.

- No single, agreed model of co-production – the way co-production is done does vary in each situation depending on the task, context and the people involved. [MH-Co-production guide 2016; Spencer et al 2013]
- It involves citizens, communities, and the professionals who support them, pooling their expertise to deliver more effective and sustainable outcomes and an improved experience for all involved. [Spencer et al 2013]
- In healthcare, this entails direct involvement of people using the service in defining the need or problem, designing the solution, delivering it, and evaluating it, in partnership with the people who provide the service. [Wiig et al 2013]
- This idea of deliberate and active participation of patients in quality improvement has become an accepted part of attempts to improve healthcare services. [Wiig et al 2013]

There is a wide variation used in the literature to describe co-production and the related practices of cocreation and co-design.

- Including among others:
    - ‘collaborative service improvement’
    - ‘participatory quality improvement interventions’
    - ‘patient collaborators’
    - ‘patient leadership’
    - ‘patient and public involvement’ (PPI)’
    - ‘patient-centredness.
- These different terms describe different extents of participation of people with lived experience to improve services and experience of care at different levels within the health and care system:
    - At the clinical services level, individuals with lived experience are co-designing their personalised care and wellbeing pathways.

    - At the organisational level, whole services are mobilising the skills and capacity of people with lived experience to deliver service improvements.
    - At the system level, local healthcare systems are working with people to co-create the system conditions for service transformation.

## Experience of care

### Putting people's experience at the heart of service re-design

There is agreement that people's experience will improve as a result of co-production, however, this outcome is not often systematically designed into the co-production process.

- Improved experience is consistently seen as a result of participatory approaches. [Kohler et al 2017]
- A key motivation for the drive for better patient involvement is to use patient experiences as an outcome measure for improving quality. [Wiig et al 2013]
- The way co-production is used as reported in the literature suggest that in many cases, service improvement based on patient experience is not often emphasised and the extent of how patient experiences are used in service improvement is often unclear.
- Two approaches emphasise the systematic collection and use of patient experiences to improve health care services:
    - Experience-based codesign (EBCD)
    - Always Events®
- Both approaches have been researched to varying degrees
    - EBCD was the topic of interest for 20 of the papers reviewed. Four papers discussed the Always Event approach.
    - Typically qualitative methods have been used in the research of co-production but there is little on outcomes and long-term impacts of the approach.
    - There was very little focus on the service users' feedback on their experience of the co-production process.
- Several very good toolkits providing practical guidance for implementing these approaches are available, for example:
    - Point of Care Foundation EBCD toolkit
    - NHS IEBD Toolkit
    - IHI Always Events Toolkit.

### EBCD and Always Events®

The distinctive features of the EBCD and Always Events approaches include:

- Giving most importance to the experiences of people using and providing services
    - There is a focus on the specific experiences of people as they move through and interact with different parts of a service with the aim of designing experiences as opposed to systems or processes.
- Emphasises the partnership and shared leadership between people using and providing services
    - People with lived experience work collectively and collaboratively with the staff to identify and agree improvement priorities, devise effective solutions, and implement changes in a systematic way.

## What influences the systematic alignment of QI, experience of care and co-production?

## Summary overview: Influencing factors for alignment of quality improvement (QI), experience of care and co-production

### System level

- National and organisational drivers have focused on performance and efficiency improvements
    - Give attention to improvements in people's experiences and not just focus on clinical outcomes.

### Organisation requirements

- Strong senior leadership commitment and sponsorship of QI and co-production
    - Leaders need to be open to rapidly translating co-production outputs into strategic decision making.
    - Leaders need to provide sufficient dedicated time and resourcing for service redesign.

- Identify and build capacity
    - Leaders need to be open to rapidly translating co-production outputs into strategic decision making.
    - Leaders need to provide sufficient dedicated time and resourcing for service redesign.

### Point of care requirements

- Engage the right people at the right time
  - Ensure early involvement and genuine partnership to identify and shape the changes.
  - Ensure relevant communities have a say in prioritising and shaping.

- Communicate openly and formalise participants' roles
  - Create a non-hierarchical structure.
  - Clearly define roles and responsibilities.

- Make it easy for people to contribute, to be valued and to have their input respected
  - Consider formal facilitation of the co-production process.
  - Pay attention to the group and power dynamics.

- Share responsibility for delivery of the changes/outcomes
  - Invest in participants – nurture confidence to co-deliver improvements.

### Valuing all

- Co-production values different forms of knowledge and evidence
  - See qualitative, narrative and storytelling approaches as having equal value to traditional, quantitative evidence. Value all perspectives.

## System level: Understanding the system level factors that influence co-production

### National and organisational drivers for efficiency improvements

Excellence in clinical care focuses on improving efficiency and clinical outcomes but often without due consideration to how it feels to both receive and deliver the care to achieve those clinical outcomes and efficiency improvements.

The current emphasis for health systems is on improving the process of care, and this has resulted in massive gains resulting in more rapid referral, diagnosis and treatment.

However, a good process does not necessarily provide a good experience for people, their families or staff. [Pickles et al 2009]

"Existing national targets have tended to focus energy on underperformance in operational efficiency, at the expense of underperformance in the transformation of people's lives." [NESTA 2013]

Services are often required to meet core targets, standards and best practice which emphasise objective processes aiming to increase efficiency and improve clinical outcomes.

Therefore, those with strategic responsibilities to the organisation, tend to emphasise objective processes over the subjective experience of people with lived experience.

However, “achieving performance targets and regulatory judgements comes as a result of tailoring improvement to where the value lies in an organisation. For example, in organisations where external targets were subordinated to their QI priorities (their ‘true north’), this has led to improvements against the targets as a consequence.” [CQC 2018]

## Organisation requirements: Influencing factors for alignment of QI, experience of care and co-production

### 1. Strong senior leadership commitment and sponsorship

### Be open to rapidly translate co-production outputs into strategic decision making

Leadership action has been shown to help align the findings or recommendations from the co-production process and ensure that they are advanced within the organisation’s relevant strategic plans and policies.

Teams need to be able to make quick adaptations and modifications as their work progresses. Hence it is necessary to cut off unnecessary layers of bureaucracy that may hinder translation of outputs into decision making.

Establish mechanisms and clear plans to act on issues raised and to continue involvement and where possible, demonstrate progress occurring between meetings. [Bombard et al 2018]

### Provide sufficient dedicated time and resourcing for service redesign

Provide adequate support, resources or managerial authority to bring about changes which reflect the priorities that have been identified. [Clarke et al 2017]

Recognise that engaging people with professional and lived experience as co-productive partners can be complex and requires time to do properly.

Traditionally when staff undertake co-production they see this as separate activity often in addition to usual clinical or managerial roles. Hence staff's frustration at the expectation that they might be expected to undertake co-production work in their own time, and that additional support was often not provided by more senior staff. [Clarke et al 2017]

## 2. Identify and address misconceptions and resistance to change

### Address preconceptions about the capacity and motivation of people with lived experience to contribute to improvement

The slow adoption of participatory approaches may reflect a reluctance among providers, many of whom do not see people with lived experience as capable of contributing to decisions that require professional expertise. [Baker et al 2016]

Studies show many clinical and managerial staff did not perceive people with lived experience and their families as well placed, at a strategic level, to assist in major redesign initiatives. [Lord & Gale 2014]

Staff assume the local population do not really understand how the health system works, and therefore, do not have sufficient knowledge and expertise to contribute usefully to service redesign. [Lord & Gale 2014]

"Challenges were experienced in convincing staff to join the project, as some physicians feared being criticized by patients on their care delivery. To overcome this barrier, much effort was put into talking with healthcare professionals and emphasizing the project's goal." [Vennik et al 2016]

### Develop capacity and confidence to engage in co-production

As equal partners in QI, people with lived experience need to be recruited based on suitable skills and behaviours, and given necessary training and development to support improvement work. [CQC 2018]

Provide training, support and guidance to staff on how to engage with people with lived experience in true co-production, including guidance on the role people with lived experience play in this approach.

Training should also address professional's beliefs about the relevance and representativeness of individual patient experiences, and their capacity to contribute to improvement.

## Point of care requirements: Creating the conditions for genuine co-production at point of care

### 1. Engage the right people at the right time

### Ensure early involvement and genuine partnership to identify and shape the changes

Having patients involved early means that their experiences and requirements can be taken into account at the start of the process and therefore help shape the planned work.

Early involvement also means patients are more likely to have a clear understanding of the project's aims and objectives, together with the strategies that would be used to achieve them, and so will be better able to work alongside other team members. [Armstrong et al 2013]

Early staff buy-in is also fundamental: clinical, management and administrative staff are busy people, yet their involvement in co-production work is vital. Staff attendance at workshops with patients gives them a unique opportunity to understand patients' experiences in a different way.

### Ensure relevant communities have a say in prioritising and shaping the changes

It is acknowledged that self-selecting patients may not be representative of the patient population more generally. Specific methods should be considered to target involvement across the patient spectrum.

Organisations should be proactive in reaching out to patients, making a conscious effort to engage with harder to hear communities. They should use different means of communication to reach different groups. [McNally et al 2015]

Studies stressed the importance of ensuring diversity and representation consistent with the broader population across different backgrounds and skills and recruitment approaches weighed against the potential for introducing biases or including self-selected participants. [Bombard et al 2018]

### 2. Explicit effort to communicate openly and formalise participants' roles

### Create a non-hierarchical structure

Patients value openness and effort to generate a 'level playing field' which means their views are not regarded as any less or more important than anyone else's.

In a supportive, workshop environment where staff and patients are equal, patients will often open up and share their perspectives in a way they would never do in the clinic room.

When there is a difference of opinion within the group, patients should be expected to engage in discussion and debate as much as anyone else.

### Clearly define roles and responsibilities

Ensure clear roles and responsibilities for patients, making certain that their involvement is meaningful, is oriented toward decisions, not just interactions, and is value-based. [Baker et al 2016]

"Different roles suited particular individuals, with participants stepping in and out of the co-design process at various stages as suited their needs, capacities and skills." [Boaz et al 2016]

Be flexible about the role patients can play and tailor to the project's context, allowing patients to develop these roles and responsibilities themselves where appropriate.

Clearly define what patients will contribute, and how they will work with other team members to achieve the project's aims. Ensure patients have the qualities and skills congruent with the chosen activities.

## 3. Make it easy for people to contribute and extend value and respect for people's input

### Consider formal facilitation of the process

Patient engagement is likely to require support and facilitation to ensure that patients can play a meaningful role as partners and co-designers in service improvement and implementation. [Boaz et al 2016]

Studies reported that in projects where facilitators were engaged formally, it was more likely that the projects maintained momentum and were delivered as planned, engaged and retained participants and generated concrete examples of areas where service users' experiences could be improved.

"External facilitation catalysed receptive contexts that encouraged user involvement by creating a positive working environment with mutual respect and equal partnership." [Bombard et al 2018]

### Pay attention to the group and power dynamics

The influence of social context, the various alliances that were formed between participants and the rigidity with which they adhered to their roles as practice staff or as patients often affected how participants responded to each other and the moderator's suggestions for change. [Litchfield et al 2018]

The degree to which patients were comfortable in sharing their views and experiences can vary according to the dynamics of the particular group.

The willingness to adopt or accept the perspectives of other stakeholders is the key rationale that underpins co-design.

## 4. Share responsibility for delivery of the changes/outcomes

### Build confidence to co-deliver the improvements

It is important to gain an understanding of patients' current knowledge and skills and to provide opportunities for patients to acquire new skills and gain confidence in service and quality improvement.

Recognise the times when patients feel that they are not responsible for certain aspects of the process or its implementation, and challenge assumptions about patients' perceived lack of knowledge or willingness to co-produce.

"Patients sometimes felt that they did not have anything more to contribute, when they feel the change process had become too technical and subsequent implementation should be the responsibility of staff." [Boaz et al 2016]

Not all quality improvement work claiming to be co-produced actually is:
"Although improvement decisions were made by both patients and staff, the inclusion of patients in the implementation process depended on the improvement theme.

"In practice it meant that patients were not involved when it was felt that they had too little knowledge about the subject; when it concerned physicians' behaviour; when it was thought that involvement was too much to ask from patients; and when it seemed more effective to only check afterwards whether patients positively evaluated the changes made." [Vennik et al 2016]

Also, when healthcare professionals thought they already had enough input from patients on how to make improvements, patients were not involved. [Vennik et al 2016]

## Valuing all: Capturing the evidence and impact of co-production

## Co-production requires collecting, using and valuing different forms of evidence

Patient experience is a complex concept not easily reducible to metrics. In spite of this, the tendency is to collect quantitative data to assess progress on "patient experience", even when the complexity and qualitative nature of patient experience is openly acknowledged. [Lord & Gale 2014]

Ironically, the challenge of assessing patient experience is sometimes used rhetorically to undermine the value of assessing patient experience because the measures used are not seen as valid or reproducible in other situations. [Lord & Gale 2014]

Narrative evidence is often thought of as being less valuable than data sets from large cohorts of patients, but in fact these stories provide more nuanced and powerful information about what really does and doesn't work. Evidence from patients that services really make a difference to their lives is difficult to argue with. [NESTA 2013]

Many NHS organisations struggle to analyse qualitative feedback such as stories and are more comfortable with quantitative analysis and data such as survey results.

Valuing qualitative feedback and quantitative evidence equally is a significant shift in thinking that the system is just starting to make. [McNally et al 2015]

It is important to think about what will be measured and how at the start and throughout the co-production process. Also, measurement tools should, in their own right, be designed to create the right experience, as well as gathering useful data. [NHSI 2009]

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Links are open access, except those marked with an asterisk (*) which can be accessed via subscription or library services.


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