Co-Producing and Co-Designing

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## **1** Introduction

The values and assumptions intrinsic to healthcare improvement are coming under greater scrutiny.<sup>1,2</sup> Many healthcare improvement approaches originated in the manufacturing sector where ideas of products and customers typically dominate. However, a belated recognition has emerged that patients are not simply consumers, but instead are active contributors to their own health and to healthcare experiences and outcomes.<sup>2</sup> At the heart of a conscious reframing of relationships between users and providers of healthcare services lies the prefix 'co'. In this Element, we consider two major approaches: co-production and co-design. Both are commonly promoted for their technocratic benefits – such as enhancing patient (and staff) experience – as well as their potential for improving quality (e.g. clinical effectiveness and patient safety). However, as we shall show, the origins of both are rooted in broader democratic rationales.<sup>3–5</sup>

We begin by briefly summarising the concepts of co-production and codesign (Section 2) and how they are used in healthcare improvement (Section 3). We use examples to illustrate key issues, but do not intend them necessarily to be representative or typical. We then describe challenges and critiques relating to the implementation of the two approaches (Section 4), before outlining the current evidence base for each (Section 5). This Element concludes with suggestions for future directions in both practice and research (Section 6). Throughout, we discuss co-design in slightly more depth than coproduction, as the former has a longer history of being applied as an approach to improving healthcare. However, we also highlight the potential implications of broader arguments for the latter as an important and revealing lens through which to practise and study healthcare improvement.

# 2 What Are Co-production and Co-design?

Though the terms 'co-production' and 'co-design' are often used interchangeably, they are not the same and have distinct origins and features. Co-production is used to recognise the two-way nature of services, that is, how the relationships and interactions between those providing and using a service influence the delivery, value, and outcomes of that service. The roles and responsibilities of service providers and users may vary, as may the degree to which the different parties consciously co-produce.<sup>6,7</sup> For example, shared decision-making is one form of co-production where a patient is encouraged to work with their clinician to select appropriate treatments or management options.<sup>8</sup> In contrast, co-design is always an intentionally applied process, used as a creative way of understanding experiences and improving services through the adoption of a range of design methods, tools, and processes that are often described as 'human-centred'. Co-design does

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not necessarily (or even typically) lead to users making an ongoing contribution to the delivery of services.

Although they are different, co-production and co-design have important similarities in their efforts to enable patients, families, citizens, and staff to work together in new ways, which is why we consider them alongside one another here. For instance, the principles of co-production (equality, diversity, accessibility, and reciprocity<sup>9</sup>) and the human-centred principles of co-design are enacted through similar mechanisms, such as dialogue, empathy, creativity, and self-efficacy.

# 2.1 Introduction to Co-production

The term co-production first came to prominence through the work of Elinor Ostrom in the 1970s. Seeking to explain variations in the delivery and outcomes of police services in the USA,<sup>10,11</sup> Ostrom's work showed differences in how actively citizens in different localities contributed to such services – for example, by reporting and taking precautions against crime. The concept of co-production has subsequently been applied to healthcare to emphasise that patients can and do play an active role not only in *producing* their own health, but also in influencing the delivery and outcomes of services.<sup>2</sup>

Interest in co-production has waxed and waned over the past five decades. At times, it appeared out of step with market-inspired reforms of the public sector, where citizens are cast as consumers. Today there are multiple, and sometimes contested, definitions, which has led to co-production being described as a 'fragmented set of activities, expectations and rationales'<sup>12</sup> used in various ways. Such ambiguities as to what constitutes co-production have led to significant variations in practice. What unites many is a recognition that users create value through their interaction with services and that organisations co-produce this with them.<sup>7,13,14</sup> In contrast, when applied in health services research specifically, the term is sometimes used to describe the co-production of research-informed knowledge through the engagement of policy-makers and practitioners with researchers (but, importantly, not necessarily with patients and service users).<sup>15,16</sup> That is not the focus here. Rather, in this Element, we think about co-production in two ways:

- as an inherent feature of healthcare. Because care is relational, service delivery is to varying degrees inevitably shaped by the interactions between patients and staff
- as a means through which to address traditional hierarchies of power and enable patients to work together with staff to improve the design and delivery of healthcare services.

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In a healthcare context, Batalden et al. recognise that both of these ways of thinking about co-production are relevant: 'healthcare services are always co-produced by patients and professionals in systems that support and constrain effective partnership'.<sup>17</sup> Because co-production is an inherent property of any system of care, not an add-on or discretionary element, the challenge is to create 'new opportunities for innovation and improvement' around which change and improvement interventions can be planned, implemented, and evaluated.<sup>17</sup> Proponents of these new ways of improving quality and safety argue that direct and meaningful input by citizens and service users is needed to shape services that are of consequence to them. This, it is proposed, can lead to better value in terms of improved quality and/or quantity of services, reflecting the needs and preferences of those who support and rely upon them.<sup>18,19</sup>

## 2.2 Introduction to Co-design

Co-design can be described both as a specific category of activity within coproduction<sup>13,20,21</sup> and as 'a conscious and voluntary act . . . concerned with how to create capacity within public service delivery systems and to improve the design and delivery of a public service'.<sup>13</sup> The approach originated in the participatory design movement in Scandinavia in the 1970s.<sup>22</sup> In a series of workplace technology projects, computer scientists and information systems design researchers took the view that 'the people destined to use the system [must] play a critical role in designing it'.<sup>23</sup> These projects drew on creative and practical methods to support a wide range of people to collaboratively identify and develop solutions to problems.<sup>24</sup> From these beginnings – and through subsequent developments in interaction, user-centred, and human-centred design (among others)<sup>22</sup> – design work and research<sup>25,26</sup> have begun to focus on healthcare.<sup>27</sup>

One contemporary way of explaining and visualising the design process is the Double Diamond (Figure 1),<sup>28</sup> which was developed by the Design Council in 2005. The Double Diamond was influenced by earlier work on creative problemsolving<sup>29,30</sup> (see also the Element on design creativity<sup>31</sup>). It remains a popular tool for explaining design to non-designers,<sup>32</sup> with the two diamonds representing a process of exploring an issue more widely or deeply (divergent thinking) and then taking focused action (convergent thinking). The first diamond is intended to help people understand, rather than simply assume, the nature of a problem – for example, through speaking to and spending time with those who are affected by the issues. The insights gathered may help to define the challenge in a different way. The second diamond encourages possible answers to the now more clearly defined problem, seeking inspiration from

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Figure 1 The Design Council's Double Diamond<sup>28</sup> © Design Council 2019

elsewhere and co-designing with a range of different people. Potential solutions can then be iteratively tested at small scale, rejecting those that do not work and improving the ones that do. Underpinning the various design disciplines and practices is design thinking, which is best understood as a human-centred mindset and approach to creative problem-solving, rather than simply a set of tools.<sup>33</sup>

The trend for greater application of design thinking in healthcare has been reinforced by the emergence of the discipline of service design.<sup>34,35</sup> Described as a 'human-centred, creative, and iterative approach to service innovation',<sup>36</sup> service design focuses on understanding human experiences and using this understanding to design better user experiences.<sup>34</sup> As such, new opportunities have arisen to use co-design approaches and tools to improve healthcare services.<sup>27</sup> Later in this Element (Section 3.3), we also discuss a distinct form of co-design called Experience-Based Co-design (EBCD), which has been

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specifically developed and used as a methodology for service-level improvement in healthcare since 2005.  $^{37-40}$ 

# 3 Co-production and Co-design in Action

In this section, we describe how the concept of co-production has been applied in attempts to improve quality and safety in healthcare (Section 3.1). We then provide illustrative examples of both designer-led co-design practices (Section 3.2) and EBCD (Section 3.3) in healthcare. Key resources that explore co-production and co-design approaches in more detail are suggested in Section 7.

## 3.1 Using Co-production in Healthcare Improvement

Co-production has become increasingly prominent over the past decade as a new way of thinking about how to improve healthcare services.<sup>2,11,17,41,42</sup> To date, co-production endeavours have tended to focus on either:

- modifying individual behaviours to better support patients to manage their own health
- · reshaping or creating new services and/or organisational processes.

One of the striking features of co-production is its emphasis on healthcare as a service rather than a product. This is in contrast to many traditional approaches to quality improvement derived from manufacturing models. In these models, the patient–professional relationship is imagined as akin to a customer–supplier relationship.<sup>2</sup> Critiques have proposed that this way of thinking risks diminishing 'the nature of the human relationships between a patient and a healthcare professional, and their contribution to health'.<sup>2</sup>

Coulter et al.<sup>43</sup> and Wagner<sup>44</sup> identify the importance of active collaboration with and involvement of people with long-term conditions in managing their own health and care. Building on such work, Batalden et al. explain how interactions and relationships between patients and staff are shaped not only by the formal structures and processes of the healthcare system, but also by the actions of local communities and wider social forces.<sup>17</sup> For example, the COVID-19 pandemic highlighted that while health and social care infrastructures often limited the potential for co-producing responses to the pandemic, this did not stop people, communities, and institutions from co-producing responses to better meet community and individual needs.<sup>45</sup> Consistent with others,<sup>6</sup> Batalden et al. propose that both patients and healthcare professionals can 'shape the system' by creating value through new and ongoing interactions within this wider context. They give two examples: an initiative to train patients and professionals to enable patients to

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self-manage chronic pain, diabetes, depression, and chronic obstructive pulmonary disease; and the use of shared medical appointments to support effective partnership between groups of patients and healthcare professionals.<sup>17</sup> These examples are typical of how co-production has more generally been interpreted and applied in efforts to improve healthcare – that is, mostly focused at the individual patient level through forms of 'engagement [that] acknowledge that patients have an important role to play in their own health care'.<sup>46</sup>

A well-known form of such engagement is shared decision-making. Interventions to encourage or enhance shared decision-making include those targeting individual patients (e.g. decision aids, 'patient activation' measures,<sup>47</sup> question prompt lists, and training for patients) or healthcare professionals (e.g. educational meetings, audit, and feedback), or both.<sup>8</sup> This focus on individual patients co-producing care through shared decision-making has been complemented by education programmes to build patients' knowledge, skills, and self-confidence and to promote self-management behaviours (e.g. Gilardi et al.<sup>41</sup>).

Initiatives have also sought to enable patients to actively engage in their own care by addressing structural issues and organisational practices. One well-known example is the establishment of a self-haemodialysis service in the Region Jönköping County in Sweden – in response to patient feedback, patients were trained and provided with facilities to perform dialysis on themselves.<sup>48</sup> Attempts to scale up the co-production of healthcare services include the development of learning health systems (see the Element on learning health systems<sup>49</sup>). A learning health system recognises that 'humans are predisposed to be cooperative and prosocial and that an appropriately designed organisation can facilitate these predispositions, thereby facilitating cooperation and co-production, at scale, to improve health, care and outcomes'.<sup>50</sup> A few published functioning examples now exist,<sup>50</sup> including the collaborative community ImproveCareNow's work with children and adolescents with Crohn's disease and ulcerative colitis<sup>51</sup> and an initiative to develop a learning health system for palliative care.<sup>52</sup>

Co-production initiatives have reported some positive results but also raise questions of equity. For example, some patients may be more able to access and engage in such programmes than others,<sup>41</sup> and governments may use co-production to transfer the costs and responsibilities of previously publicly provided services to patients themselves.<sup>53</sup> Closer consideration of the rationales for co-production may help to address such concerns. But such consideration is rare, particularly in the context of improvement practice aimed at enhancing organisational processes (albeit with some exceptions<sup>54,55</sup>).

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## 3.2 Co-design: Designer-Led Improvement Initiatives in Healthcare

In the past decade, several initiatives have enabled professional designers to work in a direct, sometimes embedded, way within healthcare systems and organisations (Box 1). These projects are referred to as 'designer-led' to distinguish them from design-based approaches, which are initiated and implemented by healthcare staff, academic researchers, and/or service users who have not received formal design training.

### Box 1 Examples of designer-led initiatives in healthcare

- At the Mayo Clinic in the USA, the **Centre for Innovation** is underpinned by design thinking and the staff members include service designers. One project explored ways to supplement existing prenatal care and provide patients and families with more ways to interact with their care team from home. The goal was to improve the patient and provider experience by designing a new model of care. A design team created 14 experiments introducing patients to new experiences and environments, such as in-home monitoring, patient-driven appointments, online communities for patients, and appointments from a distance. The team used the insights from these experiments to create a single cohesive model of care.<sup>56</sup>
- Lab4Living is a transdisciplinary research group at Sheffield Hallam University, comprising a collaborative community of researchers in design, healthcare, and creative practice.<sup>57,58</sup> The group applies design skills and creative practices to identify and formulate questions, build understanding, and create solutions. An example project developed a participatory design process for a supportive neck collar with flexibility to allow functional head movement for patients with motor neurone disease. Co-design workshops brought together people living with the disease, carers, clinicians, and designers to build understanding of optimal requirements for the collar. The project used participatory methods including qualitative interviews, 2D visualisation, and 3D mock-ups. A prototyping process led to a patented medical device: the HeadUp Collar.<sup>59</sup>
- The Helix Centre an interdisciplinary group of designers, technologists, clinicians, and researchers, based at St Mary's Hospital, Imperial College London uses human-centred design to develop clinically evaluated digital solutions for early detection of disease, effective

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treatment, and holistic care. An example project involved collaborating with a working group of over 30 national organisations to redesign the way in which difficult conversations about life-sustaining treatments are conducted and recorded, with a new form and process called the Recommended Summary Plan for Emergency Care and Treatment (also known as ReSPECT). A combination of design research insights and information design expertise enabled the co-design of a new plan, process, and visual device that brings the patient to the centre of emergency care decisions. To provide accessible training and support to clinicians, a new digital tool to help healthcare professionals learn about the ReSPECT process – through interactive training scenarios and discussion tips – was also prototyped and tested.<sup>60</sup>

One of the most comprehensively described and evaluated designer-led projects aimed to reduce violence and aggression towards staff in accident and emergency (A&E) departments in England.<sup>61</sup> Prior to the project, as many as 59,000 physical assaults were recorded to have occurred annually, with violence and aggression estimated to cost the National Health Service (NHS) in England at least £69 million a year in staff absence, loss of productivity, and additional security. The project used design practices to tackle this widespread and pressing healthcare priority. The design process was based on the Double Diamond (Figure 1) and involved extensive ethnographic fieldwork; multistakeholder work to establish priorities and how designers might best contribute; design work based on models, mockups, and prototypes; and the delivery of solutions via a toolkit and evaluation framework.

The design team collaborated with staff at the three hospitals to develop solutions aimed at improving the experience of both patients and staff, reducing anxiety, and promoting a positive hospital culture.<sup>61</sup> These included comprehensive information packages for patients and others, and a programme of reflective practice designed to better support NHS frontline staff to manage and learn from incidents of violence and aggression. The solutions were then piloted in two A&E departments. An evaluation found that staff and patients experienced less non-physical aggression, particularly threatening behaviour.<sup>62</sup> Patients' experiences were reported to have improved through clarifying the A&E process and improving the physical environment, thereby reducing frustration and potential escalation into hostility. Complaints regarding poor information and communication with patients fell by 57% (from 49 complaints during April–September 2012 to 21 complaints during the same period in

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2013). A cost-benefit analysis found that the benefits of the solutions were estimated to outweigh their costs by a ratio of 3:1. Staff also reported that the project had catalysed a cultural change through prioritising and formalising initiatives to learn from and improve staff experience, which had further positive impacts. Although the project focused on patients' experiences, patients were not directly involved as co-designers throughout this designer-led change process.

# 3.3 Co-design: Using Experience-Based Co-design to Improve Healthcare

EBCD was developed in the mid-2000s as interest in design-based approaches in healthcare services was growing. In contrast to designer-led initiatives such as the A&E project, EBCD typically sees healthcare staff facilitating a codesign process in partnership with patients. In this section, we describe the original aims and form of EBCD (Section 3.3.1), before outlining an important adaptation to the approach (Section 3.3.2) and illustrating the use of the approach as part of the Medical Research Council framework for developing and evaluating complex interventions (Section 3.3.3).<sup>63</sup>

# 3.3.1 EBCD of Services

EBCD was initially developed and piloted in a head and neck cancer service in an acute hospital in England.<sup>37,38</sup> The originators were academic researchers and designers who were seeking to draw attention to what they described as 'the burgeoning and ... exciting multidisciplinary field of interactive or "user centric design" and to the whole concept of "co-designing for user experience".<sup>38</sup> The aim was to highlight the three elements of good design – performance (efficiency), engineering (safety), and aesthetics (experience) – and to consider how these should be combined in the context of high-quality healthcare services.<sup>38</sup>

Fundamental features of the approach include a focus on the experiences of patients and staff, and the transformative potential of participating in co-design to create broader forms of value (e.g. wider health and well-being impacts). Maintaining focus on these features is seen as more important than advocating stringent adherence to a set of steps regardless of context.<sup>40</sup> The originators' intention was that the mindsets and behaviours that are encouraged and practised through implementing the approach (e.g. perspective sharing, dialogue, collaboration, and empathy) would become part of how participants seek to improve services in the future. For this reason, the approach is typically described and represented as a cyclical process.

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Box 2 The six phases of EBCD<sup>40</sup>

- (1) Setting up the project.
- (2) Gathering staff experiences through observation and in-depth interviews.
- (3) Gathering patient and carer experiences (typically through 12–15 filmed narrative-based interviews).
- (4) Bringing together staff, patients, and carers to share experiences of the service and identify shared priorities for improvement, prompted by an edited film of patient narratives illustrating significant 'touchpoints'\* of service experience.
- (5) Working on identified priorities in small co-design groups of patients and staff, using design methods (typically between four and six priorities, over three to four months).
- (6) Holding a celebration and review event.

\* A touchpoint is a point of contact or interaction between a patient and a service.

Implementing EBCD is resource intensive. Healthcare service staff usually lead its implementation alongside their usual roles. Projects typically take 9–12 months and comprise six broad phases<sup>40</sup> (Box 2) that relate to core service design practices, which involve understanding the user's perspective, making things visible, managing risk through prototyping, trying things out, and iterating ideas rapidly.<sup>64</sup> Guidance and advice on using the approach is available via a free online toolkit.<sup>65</sup>

#### 3.3.2 Accelerated EBCD of Services

Evaluation found that although practitioners found the EBCD process to be innovative and impactful, they expressed concerns that it took too long to implement.<sup>66</sup> The original developers responded by making purposeful adaptations to stage 3 of the usual approach (Box 2). In the resulting accelerated EBCD (AEBCD) process, the edited films are generated by drawing upon a publicly available, extensive, and growing national archive of filmed interviews focusing on people's experiences of their health-related conditions (www.healthtalk.org) rather than by conducting and editing filmed narrative patient interviews.

This important modification was evaluated in two intensive care units (ICUs) and two lung cancer services. It proved acceptable to staff and patients.<sup>67</sup> Using films of national rather than local narratives did not adversely affect local staff engagement and indeed might in some cases have enhanced the process; critical