Co-Designing Health Care Solutions with Patient Representatives and Clinicians in a Large Acute Hospital Setting: Process and Engagement

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Received Date: 19 December, 2022; Accepted Date: 05 January, 2023; Published Date: 10 January, 2023

Abstract

The benefits of involving patients and wider members of the public as partners in care are being increasingly recognised internationally. Co-design is one of the methods reported to promote patient-based health service improvements and offers a participatory approach to engage patients and citizens in solving health care challenges. However, current limitations are levelled at this corpus of work, indicating a lack of sustainability and substantive evidence of any known associated processes that can yield sustainable longer-term patient benefit. This service improvement project was underpinned by a Human Centred Design (HCD) methodology incorporating the Design Council’s process Discover, Define, Develop and Deliver [1]. This assisted in providing a participatory framework of co-produced work over a twelve-month period with three clinical pathway teams, Stroke, Children and Young People (CYP) and Learning and Developmental Disabilities (LD.) Meeting specific project objectives, patient-based projects were developed using a toolkit and Collaborative Action Plans that steered involvement throughout. Evaluative results elicited three themes, generating a product idea together, acknowledging the contribution of all, barriers and challenges. Within this, the clinicians and patient representatives reported the value of having a safe space to carry out experienced based work with their respective patient representatives. Additionally, they reported the chosen HCD framework guided the process of engagement determining co-produced health care solutions to patient derived challenges. Conclusions are drawn that suggest further work and research is required to testbed the ‘how to’ processes associated with successful co-design in health and social care. This could provide an empirical basis for the value and process associated with sustainable human centred design required at both a micro and macro level of healthcare.
Keywords: Co-designed health improvements Human Centred Design patient-based health solutions, Acute care

Introduction

There is increasing recognition of the benefits of involving patients, carers, and wider members of the public as partners in their care design and delivery [2,3]. The process to achieve this within Health and Social Care practice, policy and research has been widely enacted through Co-production and co-existing terms such as Co-design and Co-creation. These processes have become associated with bringing patients and communities together, with the ambition of developing equal partnerships to influence care pathways [4]. Traditionally, healthcare decisions have been made with little to no involvement of the people who will be most affected by those decisions [5]. Whilst complex modern healthcare practice has strived to move beyond this paternalistic model, the inevitable hierarchy and professional structuring within Health and Social care can still internationally present a challenge to the ambition of bringing clinicians and patient representatives together to solve service challenges [5]. Co-production aims to challenge this tacit imbalance of power held within groups of individuals, who make important decisions about other’s lives, livelihoods and bodies, particularly at the point of illness and vulnerability. Moreover, Co-design is based on long-standing practices such as community engagement and public participation [6]. Co-design therefore seeks to change this imbalance of power, through methodologically building new relationships, capability and capacity for clinicians and patient representatives through the process of co-created solutions [7]. Robert et al. (2015) [8] state that applying a Co-design approach in the healthcare context represents a radical reconceptualization of the role of patients and a structured process for involving them throughout all stages of quality improvement, with user experience at the centre. However, reported the clustered terms associated with Co-design and Co-production were still at the point of evolving and this adds uncertainty to their applicability in practice settings and also for the purposes of research.

The service improvement project reported in this paper adopted a Co-design method to work with three pathway teams in a large Acute and Community Provider in the West Midlands, United Kingdom (UK) - Stroke, Children and Young People (CYP) and Learning Disability (LD). The Nursing Hospital Executives and the teams at the outset widely accepted that involving patients in their clinical decisions and the way in which services redesign, is the right thing to do [9]. Furthermore, emerging evidence of quality improvement initiatives points to how collective thinking and sharing of experiences between patients and health professionals are essential for achieving better usage of health resources [10], particularly when supported by national standards [11].

HCD is a leading approach, which sets out to promote experience-based work. HCD is based on the use of techniques, which communicate, interact, understands and stimulate the people involved, obtaining an understanding of their needs, desires, and experiences [12]. Several fields of study have seen the incorporation of more participatory methods, such as HCD and the evolution has occurred as the design approach has been adopted more widely across different disciplines-built environment and social sciences, [13]. Increasingly, the influence of HCD approaches is growing in health systems research internationally [14]. As a ‘practice framework’, HCD integrates a three-part cyclical process of helping stakeholders derive inspiration (understanding the experiences, needs and challenges of users of community resources), produce ideation (creating ideas and solutions) and conduct, the implementation of community health strategies [15]. HCD seeks to elicit empathy for users to understand how different sets of people experience health, and address challenges and solutions within their context. It does so through adopting diverse and collaborative teams, working on action-oriented rapid prototyping based on user-derived insights, rather than from top-down approaches (Roberts et al., 2016).

The project reported here adopted a HCD approach alongside the Design Council’s method Discover, Define, Develop, Deliver [1], as a framework to complement and enhance engagement with the project participants across the three pathway teams.

Despite the volume of work in Co-design across the health and social care interface both in the UK and internationally [16], an understanding of the process that may pinpoint essential pre-requisites to achieving effective participation between patients and clinicians, has yet to emerge. The aim of this paper is to suggest that effective participation in Co-design work can be achieved, if the process of engagement in-patient led initiatives for health professionals and patients is clear from the outset and is facilitated by a human centred approach that supports experience-based solutions. The authors advocate the deliberate process of engagement and time taken to develop partnerships with the three pathway teams reported here goes some way to demonstrate this. The project objectives included:

1. To facilitate Co-production workshop(s) with key organizational personnel and their associated work stream communities.
2. To support the development of products underpinned by Co-production methods, inclusive of tangible products such as toolkits.
3. To identify the learning map that pinpoints the ‘how to’ of RWT’s Co-production associated with the selected pathway teams.
Process

Initial Engagement

During spring 2021, several meetings were held between members of Nursing Executive Team, the Head of Patient Experience and Engagement at Royal Wolverhampton Hospital (RWT) and Senior Academics from the Faculty of Health & Wellbeing, University of Wolverhampton. Following this consultation, a proposal of work was agreed with a small academic team led by MB. The executive team were able to secure monies from the Charities Board to support the projects milestones. The acute hospital provider sought to instigate co-production principles with its staff group via three selected service pathways. Distilling from a variety of metric data sources, such as Patient Feedback data, Friends and Family Tests, Complaints and the Care Quality Commission National Surveys, the Deputy Chief Executive and Acting Chief Nurse were keen to improve health inequalities for their patient populations, LD, Stroke and Children and Young People’s. For this organisation the 3 service pathways (Table 1) were made up of teams acted as pilot areas for further experience-based design work.

| Learning Disability Pathway | Specialist Nurses x 3  
|                           | Key worker from Dudley Voices Advocacy Organisation  
|                           | Patient Representatives x 2  
|                           | RWT Patient Engagement Team x 1  |
| Stroke Pathway            | Senior Nurses x2  
|                           | Physiotherapist  
|                           | Nurses x 1 plus 2 Patient Representatives  
|                           | RWT Patient Engagement Team x 1  |
| Children and Young People | Speech and Language Manager  
| Pathway                    | Clinical nurse specialist x 2  
|                           | Patient Representative x 1  
|                           | RWT Patient Engagement Team x 1  |

Table 1: Composition of Pathway Teams.

Pre-Engagement Workshops

Two pre-engagement workshops were provided to the pathway teams, one in July and September 2021. Following Covid 19 protocols, the LD workshop was provided off site (away from hospital and working environment), as it was decided engagement would be more effective than in a virtual space for the patient representatives with a learning disability. The children’s and stroke pathway joined a facilitated virtual session, which was aimed at identifying the team’s definitions and understanding of Co-production/Co-design. This initiated the process of engagement with the pathway teams and identified how they wished to structure the involvement process. Communication adjustments and alignments to form a set of co-planning principles from the outset were discussed. In essence, the workshops allowed the pathways time to discover how they (the clinicians and patients) understood their Co-production starting point and principles. It also enabled an open conversation with the challenges they currently faced within their service areas. This facilitated the opportunity to consider what solution, or product might be developed to overcome the challenges raised and how the patient voice would be ‘front and centre’ in this process. This began the application of the Discover stage of the model, which underpinned the project (Table 2).
Different definitions of Co-production/Co-Design were shared during this workshop to help clarify the co-existing and interchangeable terminology, which exists on this topic area. After further discussion, the following explanation was offered to enable the team member’s clarity on how they would be taking part in the project. The following phrase acted as a statement of intent for the project:

We will be acting as Co-creators, following Co-design methodology underpinned by Co-production principles.

The project facilitators were then able to re-message this within the face-face workshops held in the middle of September 2021 and revisit the statement throughout the duration of the project.

**Face to face Workshops**

Building on the pre-engagement activities, the 2 day off-site (away from hospital setting) workshops put the patients and clinicians service pathways through a series of Co-creation exercises together, for example establishing team co-production principles (Figure 1) and a team narrative building exercise. Building on this in the second day, enabled the teams to place the lived experience of their patient representatives at the heart of their work through the development of Collaborative Action Plans (CAP). In this way, the project Co-creators were moving through the process of mutually Defining (Design Council 2013) [1] the challenges and problems they face in their clinical pathway to identifying and making suggestions to Develop (Design Council 2013) [1] a solution focused product. This process was evidenced in the production of the CAP produced by the end of the second off-site workshop. In principle a collaborative goal focused action plan with how the patient representatives wished to be involved throughout the project, were grounded in the principles of a HCD approach [12].

**Figure 1:** Learning Disability Team Co-Production Principles.

- We want an inclusive approach that meets individual needs.
- We want an understanding that what may work for one may not work for another and that means being adaptable.
- We want a person-centred approach.
- We want to be able to give feedback and have the patient’s voice heard.
- We want improved communication and information sharing.
- We want people to get to know us by spending time to get to know us.
- At this point each service pathway was asked to secure ‘buy in’ from their wider multi-disciplinary team and begin the process of developing their products-Develop.

**Check -in sessions**

The project team were keen to maintain the momentum of the
project outside of the workshop delivery days and offer further support as the teams developed their patient focused products. A member of the project team LW worked closely with the LD pathway and off-site face to face check ins were arranged responsive to the patient reps and team’s needs over the remainder of the project. Virtual check-ins were held for the CYP and Stroke teams in November and March 2022. The project lead MB was able to assess product progress and again check in with how the pathway teams felt they were able to follow their agreed principles of Co-production.

Product Outputs

One of the project objectives was for each pathway to develop a patient-based product arising from the pathway’s Co-created service challenge. The pathway maps developed in the second workshops depicted the patient experience within each service area. From this the three pathways agreed on the specific challenge they wished to focus on and from this, a product they wished to develop (Figure 2).

![Stroke Team Pathway Map](image)

**Figure 2:** Stroke Team Pathway Map.

A key challenge for the LD team was the identification of the needs of patients with LD in a large acute hospital setting and the subsequent need for all health professionals to be trained to be able to make the reasonable adjustments necessary for this patient group [17]. Learning Disability Product -Raising Awareness of LD- was a brand logo for the patient bed space, a poster and magnetic badges, which could be used on hospital display boards (Figure 3). The hospital wide LD ambassadors, employed by the hospital to raise awareness of patients with LD, could wear the badges and raise the profile and in turn, the identification of need represented within patient group.
The Stroke team has recognised challenge was the sharing of patient information effectively with relatives across a prolonged 18-month pathway. Figure 2 represents their patient’s experience and the team’s representation of this. The Stroke Product-Communication app-enables access to patient updates for relatives across the whole stroke journey. This product would have to be developed by employing an external company. At the time of writing this paper the product was in its initial prototyping stages.

The patient representative voice from the CYP pathway was clear and active from the outset. They felt a better form of service information to help children and young people navigate, sometimes on their own, the complex range of services for children with complex needs. Children and Young People Product-Service Information Directory was a physical copy pinpointing information on services and appointments in a format that could become digitally available at a later stage.

<table>
<thead>
<tr>
<th>Discover</th>
<th>Preliminary discussions with Exec team</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Learning lessons from complaints, Friends and Family Surveys, Care Quality Commission reports</td>
</tr>
<tr>
<td></td>
<td>Preliminary engagement workshops pinpointed the Co-production starting point at the outset, some early co-production principles; first face-to-face day confirmed the patient rep voice and the starting point.</td>
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</table>

| Define   | Space provided to review the service pathway and understand what works and what could be improved, a collective discussion facilitating the patient rep voice at the centre of discussions, looking elsewhere-what do we know works? What can we do here? Consultation with division or wider MDT. Co-creating the solution begins. |

| Develop  | Face to face, workshops Co-created the team’s decision-making process; Collaborative Action Plans (CAPs) ensures the patient rep voice in product development and service redesign solution, team working and clarity of decision-making, Co-creating the pathway solution blueprint. |
Deliver

<table>
<thead>
<tr>
<th>Delivered Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaging with medical illustrators and external app/web designer’s prototyping and first iteration process.</td>
</tr>
<tr>
<td>Completed virtual checks in with pathways to explain progress</td>
</tr>
<tr>
<td>Learning Disability and CYP Products developed Toolkit developed</td>
</tr>
</tbody>
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| Table 3: Application of Human Centred Design Model (Design Council 2013) [1]. |

Evaluative Results

An opportunity was provided for all the service pathways to provide feedback on being involved in the project during the final face-to-face session towards the end of the project. A separate group workshop was held with the stroke pathway team, as they were unable to attend. All the teams were provided a series of trigger questions via a self-administered form with open text boxes collectively discussed providing a written response. Thematic analysis elicited the responses provided in the results section below [18]. The LD Patient representatives were supported by the team in this discussion enabling their feedback to be listened to and then represented visually to check for authenticity (See Figure 4). Pseudonyms are used to protect the confidentiality of the clinicians and patient representatives. The responses have been collated into the following themes- Generating a product idea together; Acknowledging the contribution of all; Barriers and Challenges.

![Figure 4: LD Evaluation Feedback.](image)

Generating a product idea together

All the three teams were asked who and how they came up with the idea for their product? In the LD pathway, one of the clinician is highlighted that the two patient representatives referred to as Donna and Doris, generated the idea based on their experience of hospital care and experience of training health professionals as ‘experts by experience’:

*Donna and Doris came up with the idea based on their lived experience of hospital care. This provided a focus for our Co-production journey (LD Clinician 1).*

Donna and Doris they reinforced this by stating how the CAP developed by all teams during the initial workshops had enabled this: *Our collaborative action plan at the beginning showed how we would be involved. We helped devise the objectives for our plan so we felt fully involved (Donna and Doris LD PR).*

All teams undertook narrative building exercises during the workshops, which enabled them to Co-create their patient journey/pathway using pictorial methods. This was an instrumental exercise assisting the teams to generate a product idea together. One of the clinicians in the Stroke pathway reflects the benefit of this exercise:
Our patient representatives were listened to, and a safe space was created for this. We also created a pictorial account of our pathway, including what was important to us as a group, and I feel this really enabled our patient representatives to express their experiences not just verbally but through other methods. This enabled us to really delve into the pathway, and from this supported us to come up with the product that we wanted to develop and co-produce as a group (Clinician 1).

The following comment from the same clinician in the Stroke pathway further illustrates how visual methods adopted in this exercise, enabled generation of a patient centred product idea for the pathway teams. It also facilitated team’s capacity to keep to goals set out in the CAPs; thereby ensuring progress could be made along the duration of the project:

Our patient and carer representatives drove the product idea, with communication being a key identified theme. The particular product of an ‘app’ was discussed and agreed amongst us all as a team. The defined problem to tackle was gained through the lived experience of our patient and carer representative, so it really was a product that was derived from their experiences of the pathway. Collaborative action plans helped us as a team to focus the project and product and have clear timescales to achieve things by. I think it is obvious that if we are going to create a product with a patient at the heart of what we do, then it makes complete sense to involve their experience of our patient and carer representative, so it really was a product that was derived from their experiences of the pathway. Collaborative action plans helped us as a team to focus the project and product and have clear timescales to achieve things by. I think it is obvious that if we are going to create a product with a patient at the heart of what we do, then it makes complete sense to involve them in the development and ideas for such a project (Clinician 1).

One of the other clinicians in this pathway also reinforced the value of the CAP:

Everyone’s contribution was acknowledged via using drawings and visual representations, an action plan we understood, sharing of information with others, lots of talking. We set dates to meet along the way. We were all open to challenge (Clinician 2).

Being open to challenge not only represents the capacity this team demonstrated for shared decision making but also confirmed the clinician’s commitment and self-awareness to value patient-based contributions.

The process of engagement adopted for the project enabled the patient representative from the CYP pathway to be very clear from the outset what the challenge was for her. This was trying to overcome and navigate her way through, often by herself, the range of different services she required. The main clinician in this pathway captures this:

Understanding all the different services and how to access and use them was a challenge glued together by our patient representative. A service information and appointment product was what she wanted… Joanne who wanted to be more in control of the information and appointment process as a young person. Joanne input was vital to ensure a realistic challenge was identified and a product possible (Clinician CYP).

Acknowledging the Contribution of All

A key feature of effective co-design is the capacity for the team to be able to make shared decisions and each team member to feel valued and enabled to express their viewpoints. Donna one of the patient representatives with LD illustrates how she felt this was achieved:

We were equal people at the table. We were able to listen and talk through our ideas. We were问题 and solution focused from the start and along the way. We were unsure of what we were doing at first but are all friends now. We feel proud now (Donna LD PR).

Levelling out the imbalance of power that can exist between patients and clinicians is a key goal to overcome with service improvement projects of this type. The following comment from the clinician within the Stroke team demonstrates a commitment to overcome any such imbalance and an integral aspect in doing so was centred on communication and valuing the ‘lived experience’ of patients:

Yes, we all absolutely agreed that communication was a key aspect that we needed to look at how we could develop and improve across the wider stroke pathway. This came through from the workshops and discussions. Certainly, from my perspective as a staff member, I recognised how important it was to hear the lived experience and felt passionate about wanting to work together with our patient/ carer representatives to produce something (a product) that met the need/ gap identified. I feel that the entire group felt like this also (Clinician 1).

This sense of partnership and engagement was supported by one of the stroke patient representatives too:

We all felt listened to each other, feedback our own lived experiences were discussed positive and negative experiences and mutually respected each other’s opinions. We felt encouraged and supported by each other in the process (Stroke PR 1).

The project was underpinned by a process embedded in patient centred values, informed by the chosen HCD [12]. The benefit of applying this framework was reflected in how the all the teams agreed on a set of Co-production principles and then abided by them through the duration of the project. The following comment illustrates how the other Stroke patient representative in the team felt this was achieved:

It felt like a great process to work through; and our principles as a group that we adhered to were the following: language, listening, individualised, relevant, respectful, sensitive, agreement, consistency, person centred care, ensuring safe spacing (Stroke PR 2).

The richness and benefit of bringing clinicians and patients together to solve their pathway challenges is reflected in the
following comment and cements the importance of acknowledging the contribution of all team members:

We were extremely lucky as a group to have a patient who had, and continues to live the pathway/journey, as well as a carer who had, and continues to support someone post stroke too. This gave us a good, broad awareness of different, but both vital perspectives. From a clinical perspective, we had nursing and AHP representation which felt like a good mix (Clinician 1).

Co-creating solutions to overcome service challenges was a key project objective. The following narrative substantiates how, from a clinician’s perspective, adopting a process such as Co-production can yield collective change:

I think the experience has taught me the absolute invaluableness of co-production when moving services forward. I think as a clinician we always think that we do what the patient/carer wants and needs, or are reactive to things that have happened, but this process has taught me so much more around how to develop and drive future change, but with the lived experience at the very heart of, all we do (Clinician 2).

Barriers and Challenges

Aside from inevitable challenges of conducting a Co-design project with busy clinicians and patient representatives from a hospital setting, the project was also conducted during the second wave of a global pandemic. Despite this and to overcome any communication challenges presented by the virtual platform of Microsoft Teams, the LD team were committed to meet face to face during the project. Whilst Covid 19 precautionary measures were followed by all team members, some concerns were still expressed: we had to be careful with face-to-face safety over the covid (Doris LD PR). The other two teams maintained their contact as functioning teams and via check-ins using Microsoft Teams. For the CYP team this enabled them to be flexible and work through some team tension and communication issues they experienced while developing their product:

The team meetings worked well for our group as we could be flexible. There was some concern from one member, where there was disagreement, they left a gap in contributions. Lots of two-way communication and checking back and forwards to ensure we understood each other (Clinician 1).

The Stroke team also had some challenges around developing their product. In essence this was more related to not having had an opportunity to develop the experience associated with product development and working with an external Design company. The following narrative from both Clinicians reflects this:

I think as the 10 months has gone on, it has been apparent that there are challenges to ensuring the success of the product development. These challenges have come from various areas which has been time consuming, however the common purpose and vision remains (Clinician 1).

We really had the idea of the product we wanted, but very little experience in developing something like this – our group chose an app. Clinically, and from the lived experience of our patient and carer, we knew what we wanted it to look like, but have no experience of the IT involved in recognising this (Clinician 2).

All the teams taking part in the project represent complex pathways and involve different health professional groupings. This was one of the first projects of its type undertaken by the organisation and as such did not have the capacity to involve all of the clinicians and patient representatives a complex pathway such as Stroke incorporates. This in part is recognised by the following comment from Clinician 1: Moving forwards, then it may be worth considering that as a complex pathway, involving other multiple MDT members, then a medic +/- other AHP representatives would also be good to involve.

Following the final consultation at the end of the project and verification of work completed during the second face to face workshop, all the teams reflected and agreed on a set of essential pre-requisites they considered were required for a successful Co-design/Co-Production work (see Figure 5 below)

Figure 5- How to do successful Co-Production

- Senior organisational ‘buy in’ from the outset with a vision to do Co-production properly and cascade the learning to the wider organisational workforce.
- Reflective, skilled and motivated clinicians with an inter-professional and patient centred value base.
- A guiding design framework to support the teams, shared and agreed from the outset.
- Real desire for a partnership with patients that negates professional identity, tribalism and enables equity in team decision making.
- Pathway clarity and ownership of agreed Co-production principles the teams all want to follow.
- Patient focused/patient-based design solution approach is intrinsic to the process.
- Co-production project objectives clear and managed.
- Demonstrable willingness by participants/co-creators to be creative and seek alternative solutions that impact positively on patients.
Discussion

This paper has presented the process and engagement associated with delivering a pilot Co-design service improvement project with three service pathways, namely Stroke, LD and CYP within a large Acute and Community NHS Provider in the UK. Engaging busy clinicians alongside their patient representatives to bring about meaningful and sustainable service improvement is a challenge. Recognising this, the project team decided to adopt a framework that structured and enabled the teams to work cohesively, and potentially could be adopted by the organisation going forward. HCD and the Design Councils (2013) [1] model of Discover, Define, Develop and Deliver married well for the purposes of this project and through a patient focused approach, selection of specific Co-creation exercises, the project team brought the teams together to deliver on the project objectives.

At the beginning of the project, it was apparent that not all the participants were aware of what Co-production was, reflecting the opaque nature of this work as represented by the cluster of associated terms- Co-production/ Co-design and Co-creation [19]. The engagement sessions set out to overcome this and the statement of intent agreed on at the outset, kept the participants ‘on track’ throughout the project. This was important as it helped the project team frame the work and the participants were referred to as Co-creators during all the sessions. The Co-creators were informed they were following a Co-design method and collectively came up with their own set of Co-production principles (Figure 1). They were behaviourally able to adopt these within the sessions and therefore stimulated the process for engagement across the teams. The importance of tone, principles and purposes for service improvement projects has been guided by the 4PI English National Involvement Standards and applied in projects elsewhere [11].

A key project output was to develop a patient-based product for each of the service pathways. Mullins et al. (2021) [6] articulate the premise upon which Co-design is built rests with perceiving ‘lived experience’ as a form of expertise. This was evident in this project, as the process demanded the teams listened and understood the patient experience, as presented by each of the patient representatives. This then became central to deciding on a product. In this case, the Co-creation exercises and project facilitation demanded this via the CAP. The patient representatives made it clear that being in control of setting objectives, as illustrated in the CAPs, enabled mutual decision making on the project choice and the CAPs acted as a reference point for the pathway work throughout the project.

An offsite venue was hired to bring the teams together for interactive sessions. Having a safe space outside of the usual working environment enabled the clinicians and patient representatives protected time. The HCD informed process in this project showed the clinicians a way in which patient voice can be central to service improvement. The clinicians in this project were capable and self-aware to allow the patient voice into the dialogue. The project team were able to set the tone of collaboration in the pre-engagement days, which was maintained across all the pathways. Critically the patient representatives and clinicians built a trusting relationship, which flattened the power, and hierarchy that can exist between patients and clinicians [20].

HCD provides the opportunity to strengthen human agency at the individual level and amplify marginalised voices through its valuable framework, tools and processes [21]. However, one of the criticisms levelled at this approach is the start and end of the process of product development and process of change that does not yield sustained improvements. This is evidenced through the well-rehearsed service improvement cycle Plan Do Study Act employed within service improvement projects across health care. Change resulting in action may occur, but it can be a challenge to sustain change long term. The executive support provided at the outset of this project were aware of this and viewed the project as a pilot of service redesign underpinned by the principles of patient-based care and Co-production. This helped the facilitation of the project as it motivated the teams as they themselves recognised they were privileged to be the first pathway teams in the organisation to have the opportunity to formally undertake patient-based design.

Co-design work relies on two critical and interlocking elements, cohesive team working and capacity to actively listen to experience-based knowledge. At a micro level, pathway teams need to work together towards a patient centred goal and at a macro level, the organisation and system it resides in, requires tested acceptance that experience based design can offer sustainable improvements [22]. The selected pathway teams in this project were complex, transcended across acute and community provision and comprised a variety of different health professionals. The clinicians within the CYP pathway, for example changed, which presented some initial cohesion issues at the start of the project [23]. However, the patient representative stayed constant throughout the project.

Conclusion

Meaningful involvement of patients that captures emotions and experience can determine existing and future patient care delivery and is a fundamental asset of human centred care. Extensive Co-produced efforts reflect this ambition, in this case in the NHS, but more widely internationally across health and social care. For the practices associated with Co-production/Co-design to become sustainable, more work is required that substantiates the intricate human practices associated with bringing Co-designed health care solutions to bear. To this end, patient centred care delivery becomes common practice and will no longer require a set of co-existing endeavours to illustrate their value. Globally,
as society moves beyond the impact of the Covid-19 pandemic, listening to and providing a committed mutual space for each other’s experience, has a heightened importance.

Acknowledgments:

The project team extend warm acknowledgments to the support and involvement of Dudley Voices and Sarah Offley throughout the duration of the project, in addition to the Charitable Funding Body at the Royal Wolverhampton NHS Trust.

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