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Increasing patient engagement in healthcare service design: a qualitative evaluation of a co-design programme in New Zealand

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Abstract

The Health & Quality Safety Commission New Zealand commissioned Ko Awatea, an innovation and improvement centre, to deliver a co-design programme to nine teams of healthcare providers. The co-design programme was part of Partners in Care, a broader programme developed in 2012 to support and enable patient engagement and participation across the health and disability sector. In the current programme teams received training, guidance and mentorship in Experience Based Design (EBD) methodology through a one day masterclass, seven WebEx sessions, coaching calls, email and through the completion of workbooks. We evaluated the co-design programme to explore the experiences, challenges and solutions that participating teams encountered while engaging with patients in their projects. The evaluation involved seventeen semi-structured interviews with programme participants, including seven team members, five sponsors, four patients and the programme facilitator. A further two team members provided feedback in written form and eight of nine teams provided completed workbooks. Data from the interviews and workbooks was thematically analysed. Health professionals identified key challenges to patient engagement as capturing diverse experiences, clear communication of project details and the availability and health of the patient. Patients advised the importance of improved communication, planning in advance and providing feedback and assurance about the value of their contribution. There are several important considerations to secure and maintain patient engagement in co-design. These include tailored strategies for approaching patients and capturing their experiences, pre-existing relationships and continued rapport building between patients and health professionals, good communication throughout the project, planning, and visibility of outcomes.

Keywords

Patient engagement, patient experience, Experience Based Design, qualitative methods, co-design

Background

The experiences that patients, the public and health professionals have when they receive or deliver healthcare services are a valuable source of information that can be used to improve care and transform services.¹⁻³

The Partners in Care programme was originally developed in 2012 by the Health Quality & Safety Commission New Zealand (HQSC) to support and enable patient engagement and participation in decision-making about their own health and the delivery of health and disability services in New Zealand. Patient engagement is defined as ‘...a process where patients of health and disability services are encouraged and empowered to actively participate in decisions about the treatment, services and care they need and receive. It is most successful when patients and clinicians demonstrate mutual respect, active listening and have confidence to participate in full and frank conversation.’³

Partners in Care included a co-design programme. Co-design is part of a process to: 1) engage with people; 2) capture patient, family and staff experiences; 3) organise the learning from captured experiences to create new understanding and insight from the perspective of the care journey and emotional journey; 4) come together in partnership to review the learning, have ideas, plan and implement improvements; 5) review what difference improvements have made.

HQSC commissioned Ko Awatea, a health system innovation and improvement centre, to deliver the co-design programme for its third iteration from October 2014 through to the end of April 2015. In this iteration, Ko Awatea worked with nine healthcare organisations to deliver content to support the core principles of the programme: 1) to achieve a partnership between patients staff and carers; 2) an emphasis on experience rather than attitude or opinion; 3) narrative and storytelling approach to identify ‘touch points’; 4) an emphasis on the co-design

of services; 5) systematic evaluation of improvements and benefits.

Programme participants used a systematic process to capture, understand and improve safety and other aspects of the care journey through the co-design of healthcare processes and services. The programme also contributed to the strategic intention assumed by many healthcare services to work in partnership with their communities to deliver patient-centred care.

An evaluation of the co-design programme aimed to: 1) describe the challenges and solutions by participating teams to increase the engagement of patients to co-design of health services; 2) describe how the approach is being embedded into daily practice, and identify opportunities to increase sustainability of the approach; 3) determine the level of leadership support provided to team members and how this impacts on the achievements and learning experiences of teams; 4) produce advice on how to engage patients in the co-design of health services.

This article focusses on the evaluation objectives that relate to patient engagement and participation, and explores the experiences, challenges and solutions that participating teams encountered while engaging with patients in their projects.

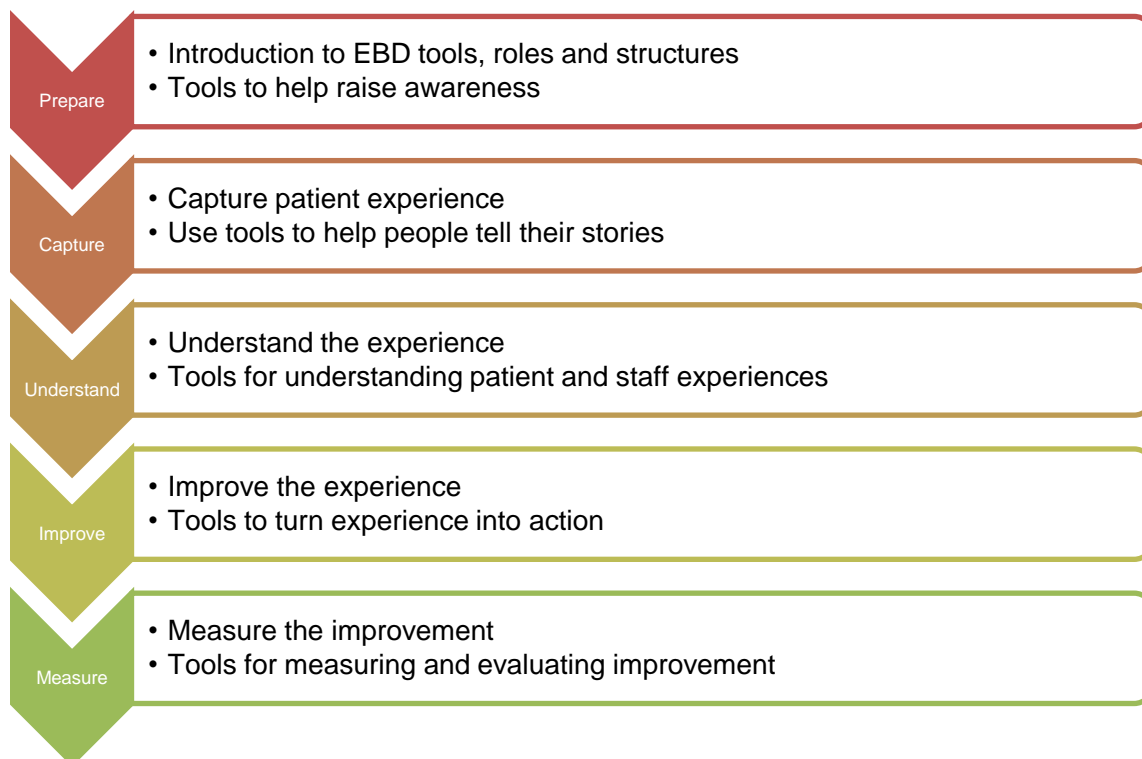
Programme methodology: the EBD approach

The co-design programme is based on the Experience Based Design approach (EBD) to co-design. EBD is an evidence-based approach developed by the National Health Service in England.²⁴ It uses patient and staff experience to design better healthcare services, and was successfully used to support delivery of two previous iterations of the co-design programme in 2012 and 2013. EBD has also been applied in other healthcare services, for example in England, Canada, the USA, Australia and New Zealand.^{1,5-8} The approach draws out and captures the subjective and personal experiences of patients and carers who use healthcare services, and of those staff who deliver healthcare services. This ensures that healthcare professionals understand experiences from the perspective of staff, patients and carers. The EBD approach entails the use of a specific process, which has been adapted for use in New Zealand (Figure 1).

Programme delivery

Project teams from nine healthcare providers participated. Collectively, this included 56 healthcare professionals and 17 patients. Patients engaged at one of two levels: patients who contributed feedback, information and perspectives about their healthcare experiences to project teams; and

Figure 1: Summary of project phases for the Partners in Care co-design projects⁹



patients who played a dual role in contributing feedback, information and perspectives, but also actively participated in ongoing communication and decision-making alongside project teams. Participation in the co-design programme commenced with project teams (comprising both health professionals and patients) attending one of two masterclasses. The masterclass aimed to increase participants' competencies in: 1) understanding the context, value and evidence base for working closely with patients and their families; 2) awareness of a staged process to engage patients, capture their experiences of care, organise and identify themes for improvement and to co-design future services; 3) knowledge of a range of specific customer service design methods including observation, shadowing, interviewing, emotion mapping and co-design; 4) application of these methods to National Patient Safety Campaign work streams. The masterclasses included a mix of presentations, group work, and discussion to maximise learning.

Following the masterclasses, participants received ongoing education in co-design methodology, mentorship and support through seven one-hour WebEx sessions. These incorporated formal teaching and opportunities for participating teams to share their progress and ask questions. In addition to the formal teaching delivered at the initial masterclass and subsequent WebEx sessions, the programme facilitator provided further guidance through coaching calls and email as required.

During the programme, participants completed a workbook and case study template. Workbooks were completed by each project team twice throughout the programme period to capture learning over the duration of the programme. These were reviewed twice by the Ko Awatea programme facilitator to provide feedback and direction as teams progressed through the programme. Workbooks captured: 1) evidence of each project team's work and feedback from each phase of the co-design approach; 2) descriptions of how the team have engaged leaders, staff colleagues and patients including what worked well and any challenges they had faced; 3) practical experience of utilising tools and methods that increase the engagement of patients and lead to co-design of health services; 4) stories/narratives that demonstrate the impact of working closely with patients; 5) the impact that participating in this programme has on them as an individual, patients they are working with, other people working with them and the organisation they work for. The case study template captured a 500 word case study describing each project.

Programme participants also had access to a wide range of resources and learning material through the HQSC website. This included relevant peer-reviewed papers, other helpful documents and website links about patient experience. They could also share their own learning

resources and useful documents with other participants through this website.

Project sponsors are leaders within participating organisations who assume responsibility to support project teams through the co-design process. Depending on the needs of project teams, this support may involve being present for webinars or project meetings, assisting teams to socialise the co-design approach at different organisational levels, helping teams to problem solve when they encounter barriers, and connecting professional networks when the work of project teams requires the input of other staff or services.

Evaluation approach

The evaluation framework for the co-design programme was developed jointly by the Research and Evaluation team at Ko Awatea, the programme facilitator and the HQSC Partners in Care director. The evaluation applied qualitative data collection methods to gain in-depth information from key stakeholders to meet evaluation objectives. Data collection methods used were: 1) study and analysis of teams' workbooks, completed case study templates and presentations for contributions to WebEx sessions; 2) semi-structured interviews with team members and sponsors; 3) semi-structured interviews with patients; 4) semi-structured interview with the programme facilitator.

Completed workbooks from each team were provided directly to the Research and Evaluation team by the programme facilitator with the consent of participants, twice throughout the programme period (January and June 2015).

The programme facilitator made initial contact by email with members of participating teams, sponsors and patients. The purpose of the initial contact was to introduce the lead investigator, and communicate evaluation objectives and key points around typical evaluation queries potential participants may have. The contact details for the lead investigator were also provided so that participants could make contact about any questions, concerns or complaints about the evaluation.

Following initial contact, all potential evaluation participants were provided with information detailing the evaluation objectives, participant requirements, risks, and use of data. For those who did not respond follow-up contact included email reminders and phone contact. For those who did respond, a short survey was sent to assist with interview scheduling. Interviews were then confirmed by phone.

Due to the location and preferences of evaluation participants, most participant interviews with sponsors,

Table 1: Question subjects in interview schedules for stakeholder groups

| Stakeholder | Topics |
|-----------------------|---|
| Team members | <ul style="list-style-type: none"> • Staff experiences of approaching patients • Securing participation from patients • Guide for approaching patients • Learning and sustainability • Support from sponsors • Opportunities for improvement |
| Sponsors | <ul style="list-style-type: none"> • Support offered • Learning and sustainability • Opportunities for improvement |
| Patients | <ul style="list-style-type: none"> • Approaching patients about the co-design programme • Motivators and disincentives for participation • Participation experiences • Participation outcomes and general satisfaction • Opportunities for improvement |
| Programme facilitator | <ul style="list-style-type: none"> • Staff experiences approaching patients • Learning and sustainability • Support • Opportunities for improvement |

team members and patients were conducted over the phone. A face-to-face interview was held with the programme facilitator and one patient.

Questions in the interview schedules were grouped around topics (Table 1).

Data sources

In total, 17 semi-structured interviews were conducted, involving seven team members, five sponsors, four patients, and the programme facilitator. A further two team members provided feedback in written form. The interviews were conducted at the conclusion of the co-design programme, in a six-week period spanning May and June 2015. Completed workbooks were obtained for eight of the nine healthcare organisations participating in the co-design programme. Due to staff turnover, one healthcare service was unable to complete the final workbook. Finally, the Counties Manukau Health Consumer Council also provided feedback around patient engagement in co-design projects.

Analysis

A written record of each evaluation interview was sent to the interviewee for verification and to highlight any missed points. Interview records were then de-identified to protect the confidentiality of evaluation participants, and thematically analysed. Workbook materials were filtered for relevance to evaluation questions and thematically analysed alongside interview data.

Findings

The focus of the co-design projects varied (Table 2).

Findings are presented in three stages of patient engagement: the planning phase, the first encounter and maintaining patient engagement.

Planning phase

Before engaging patients, project teams prepared by (i) considering key patient characteristics which were relevant to their project, (ii) defining the scope, direction or issue to address for their project (to varying extents), and (iii) planning pathways for approaching patients and the use of different experience capture tools.

Team members described having clear criteria for patients they approached in the planning phase of their projects. They looked for patients with recent experience of the relevant health service or procedure; advocacy or communication skills; interest and availability to become involved; and, in some cases where relevant, demographic qualities such as age or gender. In many instances these patients were well known to healthcare professionals:

“We knew who would be a good patient in this ... They were vocal, available and a good advocate for themselves.”

Table 2: Summary of the project aims of participating teams

| |
|---|
| Improve understanding of the ACP (Advance Care Planning) process and resources from Pacific health workers and Pacific patients' perspective. |
| Support improved way-finding by patients through patient perspectives about the effectiveness of signs from the hospital gateway to their destination, and finding their way back out to the carpark. |
| Identify the most appropriate ambulance response for patients who have fallen but do not need transport to the Emergency Department, but may require assistance to get off the floor and assessment of their ongoing risk of falls. |
| Reduce the overall harm related to opioid use in orthopaedic theatre patients by 50% by June 2016. |
| Provide an outpatient hysteroscopy service. |
| Investigate patient experiences of referral processes into the District Nursing Service, and how we can foster relationships with patients of the service. |
| Increase the engagement of patients in decision-making about the services they use, and to increase patient literacy and capture patient experiences. |
| Identify high risk vulnerable patients, develop shared care plans for these patients, identify emerging issues, and establish proactive care planning that can be accessed by all services. This is to provide a streamlined health service where important health information is shared between patient, family and providers. |
| To capture the experience of youth using Supp Clinics, and also their experiences of the previous CAMHS (Children and Adolescent Mental Health Service) services. |
| Work as a multi-disciplinary group with patients to improve communication with patients around falls risk and reduction initiatives with the ultimate aim of reducing the incidence of falls. The focus was predominantly on the inpatient environment, specifically wards with a high incidence of falls. |

An agreed understanding of key patient characteristics needed for each project team was used by team members to determine whom they would approach. This process provided reassurance to team members that the patients approached would be relevant in their experiences and potential contributions to the team.

However, project teams acknowledged the risk of reducing diversity in the patient experiences captured. Whilst team members felt they were able to reach patients who were (i) interested, (ii) available, (iii) capable of articulating their story, and (iv) had a relevant patient experience with the service involved in the project, this was often at the cost of excluding patients with poor health literacy and/or those who found it difficult to engage with health services. Further, because the involved patients were health literate and had good advocacy skills, they were often complimentary in their perspectives and experiences of healthcare services. Positive stories provided a valid patient experience and were valuable in identifying what was working well within healthcare services. However, team members found negative patient experiences particularly useful in identifying areas for change. As summarised by one health professional:

"We know we are not perfect. There is room for improvement somewhere."

Upon reflection, planning multiple pathways for approaching patients and different experience capture tools was one method that staff recommended to increase the diversity of patients engaged in co-design projects, and understand both positive and negative patient experiences to help refine their project direction.

The first encounter

A clear theme emerging in patient accounts of their experiences participating in the co-design programme was that there is no single 'right way' to engage patients. Team members reflected on the need to tailor strategies for approaching patients and capturing their stories based on patient groups and individuals concerned:

"There is more than one way to approach patients in the capture phase. Teams should have alternative plans to utilise if you don't capture any patients in your first approach ... and how you get patient feedback should be tailored to the particular patient ... In the planning phase, explore a few different options and offer alternatives to patients so they can provide feedback in a way they are most comfortable with."

"Patients were encouraged to share their stories in a variety of ways. If you can't describe it in words, use photos, or just give me some key words."

One team member described developing experience capture tools in conjunction with patients as a key lesson:

"Preparing the survey document in conjunction with patients [ensured] it was usable for them [in terms of] language, question structure and relevance."

Table 3: Contact platforms used by team members to approach patients

| | |
|------------------------|--|
| Face-to-face | <ul style="list-style-type: none"> Planned face-to-face discussion with patients in the inpatient setting, facilitated by health professionals known to the patient Planned face-to-face discussion with patients through outpatient/community services, facilitated by health professionals known to the patient Opportunistic face-to-face discussion with patients or other members of the public in healthcare service settings |
| Telephone | <ul style="list-style-type: none"> Telephone contact to previous patients by service receptionist, team member or patient representative, using patient records to identify eligible patients Telephone contact using complaint or incident records |
| Email | <ul style="list-style-type: none"> Email contact to known patients facilitated by the team member |
| Promotional approaches | <ul style="list-style-type: none"> Promotional materials displayed in public locations within health services for people to self-nominate their involvement Patient experiences captured in public locations, e.g. Post-it notes on photo boards where patients can anonymously leave information Promotion of the project through existing patient networks (e.g. patient councils) |

Table 4: Story capture methods utilised by project teams

| | |
|--------|---|
| Team A | Patient interviews |
| Team B | Patient interviews |
| Team C | Patient interviews and observation |
| Team D | Patient interviews and process mapping |
| Team E | Patient interviews (phone), process mapping, suggestion box and patient questionnaire |
| Team F | Patient interviews and process mapping (video) |
| Team G | Patient interviews and patient questionnaire |
| Team H | Patient interviews, patient questionnaire, observation and photo-board |

Contact platforms used by team members are shown in Table 3 and story capture methods in Table 4. Although all strategies (Table 3) were successful in securing patient involvement, patients expressed a preference for a more personal approach. Table 4 shows that teams utilised one (25%), two (50%) or more (25%) methods to capture patient stories.

Relationships were important in the initial approach, as well as ongoing patient engagement in the project. All four of the patients interviewed were approached by a known health professional. This familiarity and trust from a pre-existing relationship were paramount in the patient coming on board with limited understanding and information about the programme and what was involved: *“She [the nurse] had helped me through a couple of difficult periods ... The fact that I knew her helped.”*

Team members whose services did not afford opportunities for ongoing contact or rapport building found patient engagement more challenging and were uncertain about the most appropriate way to approach patients. This required them to draw on existing groups including patient councils, community-based groups such as churches, and extended care networks.

Regardless of the nature of the relationship between patients and the healthcare professionals who approached them about the project, patients communicated the importance of health professionals: 1) being personable and approachable and committing to rapport-building with patients; 2) providing patients with space to think about their involvement (not expecting a response straight away) and reflect on their contribution; 3) making it okay to say no, and not pushing for their involvement if the patient is not interested; 4) explaining in simple, non-medical jargon, what co-design is and expected outcomes; 5) being honest

and transparent about patient involvement, including time commitments, how the information will be used, and any compensation available; 6) assuring patients they have a worthwhile contribution to make; 7) really listening without judgement and validating the experiences of patients; 8) being genuine and empathising where you have similar experiences; 9) using simple language that is not full of medical jargon.

Timing was an important consideration in making the first approach to patients. Team members recognised that it was important not to leave contact too long, but also acknowledged that there are inconvenient or inconsiderate times to approach patients. Patients identified the following as inconvenient times to be approached: 1) at vulnerable times – for example, in acute care settings where they could be experiencing pain or be focussed on their health condition and recovery; 2) for some, when they have family or friends visiting with whom they would like to spend time and dedicate their attention. However, others appreciated the availability of support people.

For patients working at project level, two team members highlighted the value of the patient being involved as early as possible in the project development, so they are familiar with and contributing to decisions made. These health professionals argued that early involvement would provide the patient with great context around why a particular solution was being pursued: *“Knowing a project inside out makes it easier to understand what is happening now.”*

Health professionals working with patients at a project level experienced challenges communicating clear expectations about the patient role and the time they would have to dedicate to the project. Due to the evolving nature of the projects, health professionals initially felt uncertain about what they were actually asking patients to do, and often reported wishing that they could have been more upfront about what was involved. However, such details were rarely possible to anticipate. Contrary to the discomfort of health professionals in trying to communicate clear project details, the immediate response of patients who worked at project level with the team was feeling honoured about being approached: *“[My first thought was] this is neat. This is a real privilege.”* Initially, what was most important to patients was: 1) being given an opportunity to help; 2) being reassured that they can help and have a worthy contribution to make; 3) understanding the importance of patient perspectives in co-designing healthcare services.

For patients, their participation was value-driven and highly personal. Patients were motivated to become involved by altruistic and community values: *“If you can make a comment which improves things, that is all you wish for.”* Six out of seven health professionals (85%) found that patients were highly receptive to the offer of being

involved in co-design projects. To maintain ongoing engagement, however, all patients, regardless of their level of involvement, needed some awareness of the commitment they were making.

Maintaining patient engagement

Patients recommended regular communication, advance notice of meetings and other commitments, and regular feedback that they were making a worthwhile contribution to maintain patient engagement in co-design projects.

Adequate resources and support made it possible for patients to maintain engagement. Some teams paid patients for their time or offered petrol or taxi chits as compensation for the cost of travelling to and from meetings. One patient identified the taxi chits as a key enabler in their ability to contribute to the project. Another noted that, *“Being paid isn’t the be all and end all ... [but it did make me feel that] ... they were taking this seriously ... [and that] my contributions counted for something.”*

Health professionals saw competing demands on patients’ time and health conditions limiting the patient’s ability to participate in the project as barriers to maintaining patient engagement. Engaging more than one patient to work at project level with the team was identified as a solution to challenges with patients being unable to contribute on a long term basis to the project (for various reasons such as their health, availability, or familial commitments). For example, one project team commenced the project with three committed patients working at project level but, over time, retained one patient who contributed actively throughout the project period.

Visibility of the end result emerged as a critical factor in patient engagement and satisfaction with their involvement in the co-design projects. All patients reported having a lack of information about project progress or outcomes, which left them feeling frustrated or dismissed: *“Their need of me is gone, I suppose ... Maybe something else will come up that I can be involved in.”*

Patients relayed that this lack of communication was often the result of workforce turnover, competing priorities and reassignment to other projects which resulted in changes to clinical staff whom they previously identified as project drivers and key contacts: *“The [project manager] has been dragged into some other project, they have about five on the go at once.”*

Lack of communication about the project outcomes was disappointing for patients because, in juxtaposition to their need to help others, they felt unclear about how they had helped, whether their input had made a difference, and how others might have a better experience of health care services as a result of their work.

Discussion

The value of co-design approaches is well established in existing literature.¹⁰⁻¹⁶ This article provides direction for enhancing co-design processes to optimise value for both patients and healthcare professionals. While many studies have involved patient participants,^{11,13,16-24} few have offered an in-depth exploration of patient experiences of their engagement in co-design.

The evaluation objectives relating to patient engagement focussed on describing the challenges and solutions by participating teams (including patients) for planning, initiating and maintaining the engagement of patients in co-design projects. Key challenges included: 1) securing a diverse range of patients and patient experiences; 2) reaching and approaching patients in the absence of pre-existing relationships; 3) communicating clear project details and commitment requirements to patients when projects were still evolving and such details were unknown, and 4) availability of the patient.

Patients and team members proposed many solutions to the above challenges. These included drawing on pre-existing relationships, patient and community groups to connect with patients, tailoring approach and story capture methods, and committing to rapport building with patients regardless of the nature of pre-existing relationships. Initially, patients were motivated to become involved in co-design projects by the belief that they could contribute to service improvements, feeling honoured to be given an opportunity to help and understanding the importance of patient perspectives in co-designing healthcare services. However, an awareness of the time commitment required, roles and responsibilities is needed to maintain engagement.^{23,24} Further details about the objectives and strategies of the co-design projects were developed with the patients once involvement had been secured. Early engagement allows advance planning to take patients' experiences and requirements into account, and helps patients to develop a clear understanding of their role and responsibilities.^{1,24} Lack of advance planning by some project teams inhibited patient participation.

Availability of patients could be limited by competing demands on patients' time or by patients being too unwell to participate or having health conditions which inhibited their involvement. The need to have more than one patient engaged at project level was a key lesson from the co-design programme. Bak *et al.* note a 50 per cent patient attrition rate for some EBD teams.²³

There is no 'one size fits all' approach to patient engagement and story capture. Included in this article (Table 4) and others^{4,22} are examples of many ways that patients can be approached and provide feedback during the co-design process – questionnaires, interviews, photo-

boards and videos, for example. Using more than one option allows experience capture methods to be tailored to individuals and patient groups, enabling patients to communicate in ways they are comfortable with. The current and previous studies^{22,25} have identified that securing a diverse group of patient participants in co-design is challenging. Involvement across the patient spectrum is important to ensure a representative spread of patients.¹ Vulnerable populations, such as those facing language barriers, low health literacy or low income levels, face greater challenges in motivation, willingness and ability to engage.²⁶ The experiences of these patients are potentially a rich source of ideas for change. We propose that providing choices for engagement and story capture is not only preferable for patients, but may assist in increasing the diversity of patients and patient experiences captured.

Relationships and trust are central to meaningful patient engagement. Relationships and network-based strategies are more effective for reaching patients than impersonal approaches.²⁷ A commitment to rapport-building enabled honest and open feedback from patients about their experiences. In addition, developing a rapport between patients and project teams (rather than one health professional) would have helped to maintain ongoing engagement in the event of staff turnover.

Patients made some important recommendations to maintain patient engagement throughout the programme, including improving communications, planning in advance and providing assurance or feedback about patient contributions to projects. Because patient participation in co-design projects is value-driven and personal, providing assurance that patients are making a valuable contribution throughout the co-design journey is important to maintain motivation and engagement.³ Patients in the co-design programme would have valued ongoing contact and follow-up about how their contributions had been applied, solutions that had been implemented and the impact on other patients utilising health services as a result of their involvement. Supporting previous findings by Bak and colleagues²³, we highlight that patients cannot always stay engaged throughout the entire co-design process, and therefore feedback about patients' contributions may be needed at different stages of the project timeline, including beyond the formal project period.

Limitations

As interviews are a verbal exchange, effective interviews are largely dependent on the communication skills of interviewers.^{28,29} The interviewer leading this evaluation has significant experience conducting interviews, and used techniques such as pausing, probing, prompting and allowing free conversational flow to encourage sharing of experiences and insights related to the programme.

Due to the voluntary nature of participation in this evaluation, the number of evaluation participants is limited. Having clinical staff participate in evaluation activities is difficult given their limited time capacity during the working hours. Interview times were flexible to facilitate participation.

The evaluation had a qualitative focus. It is therefore able to capture in-depth the experiences of sponsors, team members and patients participating in the co-design programme. It did not, however, involve the collection or analysis of quantitative data, and therefore rigour is more difficult to maintain, assess, and demonstrate.

Conclusion

Many patients are supportive of the concept of co-design and interested to work in partnership with health professionals to improve services.

There are several important considerations to secure and maintain patient engagement in co-design. These include tailored strategies for approaching patients and capturing their experiences; pre-existing relationships and continued rapport building between patients and health professionals; good communication throughout the project; planning; offering patients adequate resources and support; and visibility of outcomes. Consideration needs to be given to patients' health conditions. Patients' health, along with other factors (for example, family and work), may impact on the amount of time they are able to contribute.

If co-design is to become a true partnership between healthcare providers and patients, more attention to laying the foundation for this methodology is needed.

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