THE NEW ZEALAND
MEDICAL JOURNAL
Journal of the New Zealand Medical Association

NZMA
New Zealand Medical Association

Improving healthcare through the use of co-design

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Abstract

Aim This paper describes how co-design methods can be used to improve patient experiences and services within healthcare organisations. Using the Patient Co-design of Breast Service Project as an example, we describe how patient experiences were captured and understood, the improvements made and implications for future work.

Method We used a six-step process: engage, plan, explore, develop, decide and change. Tools and techniques employed were based on service design approaches. These included patient journey mapping, experience-based surveys and co-design workshops.

Results Information, communication, navigation and co-ordination, and environment emerged as key themes for the Breast Service. And as a result, a suite of improvements were made. Key methodological learnings included using co-design alongside traditional quality improvement methodologies, engaging with patients early, the importance of staff buy-in and the necessity of trying things outside one's comfort zone.

Conclusion Use of co-design within the Breast Service has resulted in tangible improvements and has demonstrated the value of engaging patients and focussing on their experiences. It is recommended that: evaluation phases are factored into future co-design work, further research is conducted on sustainability and funding and support is given to allow co-design to become more widespread throughout New Zealand.

Co-design challenges the existing quality improvement paradigms commonly used in New Zealand hospitals in three major ways. Firstly, it encourages patients to take an equal role in the review and development of services. Secondly, it focuses strongly on designing services around patient experiences.[1] Thirdly, it uses techniques and tools derived from service design—e.g. prototyping and storyboards, rather than manufacturing environments as well as process maps and statistical process control.[2,3]

Within a health context, co-design (also known as experience based design or co-production) is "… a method of designing better experiences for patients, carers and staff".[4] It involves patients and staff exploring the care pathway and the emotional journey patients experience along it, capturing experiences, then working together to understand these experiences and improve them.[4]

Co-design's innovative way of actively involving patients in healthcare design has been gaining traction overseas for a number of years. Originally piloted in the Head and Neck Cancer Service in Luton and Dunstable, UK, (in 2006) it has successfully spread to other parts of the UK and Australia and more recently New Zealand.[5] The range of health services where co-design has been applied now includes head and neck cancer,[6] renal, dementia,[7] dietetic, orthopaedics, emergency departments[8,9], mental health and gynaecological outpatients.[9]

The changing role of patients and their families/whanau in quality

Traditionally patients and their families were seen as passive recipients of health services but in recent years the importance of more meaningful consumer input into the review and design of services has gained currency.[6]

District Health Boards (DHBs) and their predecessor organisations have historically endeavoured to listen to and incorporate patients' perspectives through mechanisms such as the complaints (and compliments) process, surveys, feedback boxes, representation on reference groups, health literacy groups, consultation meetings and hui and so on. Service improvement and quality projects, too, have recognised the value of listening to, and understanding, patient perspectives.

The way in which patients have input into service improvement in healthcare in New Zealand is gradually evolving from what Bate & Robert[1,6] describe as a passive (or low involvement) patient mode towards a partnership approach on the 'continuum of patient influence' scale. This change has been influenced by[6]:

- The proactive approach of various industries to improving customer experiences.
- The growth of service design.
- A more organised and active consumer voice.
- The prevalence of instant public feedback via the internet and social networking technologies.

Co-design approach

In our New Zealand work, co-design projects incorporate six main elements or phases.[10] The first three elements are primarily about capturing and understanding the patient experience. While the latter three focus on improving the patient experience.

- *Engage:* proactively establishing and maintaining meaningful relationships with patients (and staff) to understand and improve health services.[11]
- *Plan:* working with patients and staff to come up with ideas about the goals of the improvement work and how to go about doing it.
- *Explore:* learning about and understanding patient and staff experiences of services, and identifying things that can be improved.
- *Develop:* turning the ideas into specific improvements.
- *Decide:* choosing what improvements to make and how to make them.
- *Change:* turning improvement ideas into action.

While described as a series of steps, in reality each element may overlap and the order, and even the omission, of some elements is not necessarily important. The common element is the active engagement of patients and their families in each activity undertaken.

The core principles underpinning our co-design work are equity, understanding experiences and improving services.[10]

This paper discusses how Waitemata DHB, through its Patient Co-design of Breast Service Project, has worked with patients and staff to improve the breast journey and, on a small scale, trial a methodology not yet widely acknowledged or used in New Zealand.

Method

The Breast Service at Waitemata DHB provides services at both North Shore and Waitakere Hospitals. At the time of the project, the Service comprised two breast nurse specialists, four surgeons and four oncologists. Weekly surgical and oncology clinics were held at North Shore Hospital. Breast surgery was performed at both North Shore and Waitakere Hospitals. The Breast Service averaged more than 2,500 referrals per year and approximately 10% of these resulted in a diagnosis of breast cancer.

In 2007, the Patient Co-design of Breast Service Project was set up to work alongside a sister project focussed on improving the referral process and developing clinical guidelines for patients with breast disease. Its aims were to use an innovative co-design approach to understand patient experiences, make small, focussed changes with patients, make further recommendations for changes in the service and develop a model for working with patients that could be used in other services. Further, it strived to involve patients in a deeper, more participatory way, than previously had been done.

In order to capture and understand patient experiences, a number of tools were used. Each tool used produced results which then influenced the type of tool which would be used next and the overall direction of the project. The tools were: patient journey mapping, experience-based surveys and co-design workshops.

Patient journey mapping—A patient journey map is a summary of the service experiences patients have over time. It includes patient journey phases, the people they have contact with, the emotions they experience during their journey, touch points (significant points of contact—tangible and intangible—that patients have with the Service) and suggested improvement ideas.

Twenty-one people attended a journey mapping workshop including patients and their supporters (14), staff (5) and workshop organisers (2). Participants were guided through the development of patient journey maps in groups. These were subsequently developed into a summary map (Appendix 1). Participants discussed ideas for change and improvements at the conclusion of the workshop and came up with a summary list of improvements.

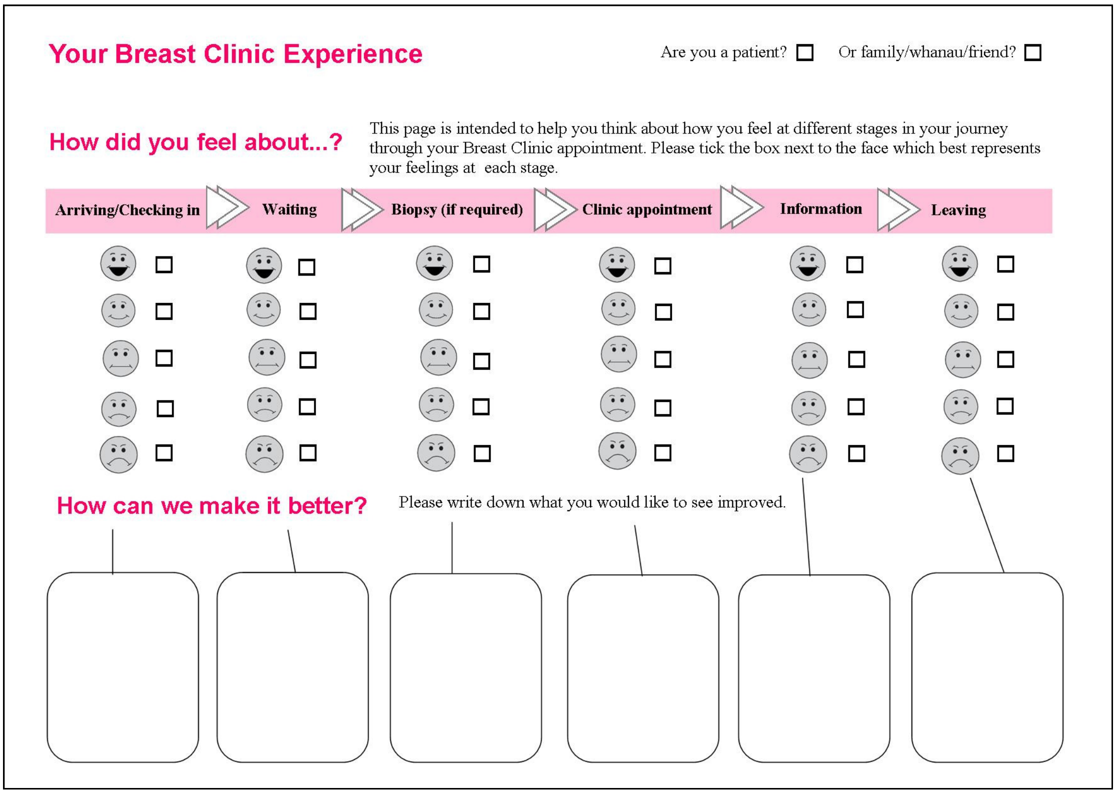
Experience-based surveys—Experience-based surveys are one-page surveys to find out how patients experience a specific part of the hospital journey. They allow patients to come up with specific suggestions for improving their experiences.

To gain a deeper understanding of patients' experiences, and to ascertain benchmark data for the Service, we developed an experience-based survey (adapted from the NHS) (Figure 1).

Over a 6-week period, all patients who attended a Breast Clinic appointment or a mammogram were given a survey. The survey asked patients and their family/whanau to rate their experience of elements of their journey. 182 surveys were completed (97 from those attending a breast clinic appointment and 85 from mammography/ultrasound) representing approximately 31% and 14% response rates respectively. It is important to note that the surveys were not intended to be scientific and as such no demographic information was collected. Further, responses were sought passively and were not followed up which is likely to have affected the response rate.

Co-design workshops—Co-design workshops involve a wide variety of people who have an interest in the project getting together in one place to discuss issues, learn together and make decisions. These workshops may be based around starting up a project (start-up or planning workshop), understanding patient or staff experiences or delving in depth into an issue (journey mapping or ideas groups) or coming up with tangible solutions (using tools such as prototyping).

Figure 1. The breast clinic experience survey



Your Breast Clinic Experience

Are you a patient? ☐ Or family/whanau/friend? ☐

How did you feel about...?

This page is intended to help you think about how you feel at different stages in your journey through your Breast Clinic appointment. Please tick the box next to the face which best represents your feelings at each stage.

Arriving/Checking in **Waiting** **Biopsy (if required)** **Clinic appointment** **Information** **Leaving**

How can we make it better?

Please write down what you would like to see improved.

The co-design workshop aimed to find out:

- What information given to patients was most useful?
- What other information would patients find useful to improve their experiences?
- When is the best time to get this information?
- What format would people like information provided in?

Twenty-nine people attended including patients and their supporters (12), staff (11), community group representatives (3) and workshop organisers (3). We asked participants to talk about their response when they had the 'right' information and what difference the 'right information' could make to them (Table 1).

Table 1. Information dynamics

Without right information	With right information
Extremely upset	Confidence
Angry	Powerful, empowered
Frustrated	Competent
Scared	Trust
Confused	Relief
Anxious	Empathy
Bewildered	Partnership
Pressured	Understood
Let down	A whole person, not just a number
In conflict	Supported

In small groups, participants then identified what they needed to know at each step in the journey, why they needed to know it, how they could best find out about it and the best media or format for the information.

Results

Patient journey mapping—Participants identified a range of improvement ideas (see Table 2). There was an agreement that many improvements were oriented towards the beginning of the journey because they have the capacity to influence everything else that follows.

Table 2. Key identified improvements summarised by phase

Journey phase	What patients wanted	Tools and actions suggested
Symptoms	Encourage women to go to their GP earlier for check-ups.	Develop diagnosis and referral guide for GPs.
Diagnosis	A supporter with them when they had their results appointment (and for any other such meetings where they might be told bad news).	Staff to recommend and emphasise the benefits of this when the appointment is made.
	Kind and empathetic staff.	Have patients give talks about their experiences and problems to staff and patients on training courses.
	A 'host' for women on their entry to the Service to act as their 'navigator' through their journey.	Provide one constant point of contact throughout the whole journey.
Treatment	The option of a longer stay in hospital after surgery to prepare psychologically and practically for the return home.	Help people prepare for recovery at home, building their confidence and skills (method to be decided).
	Minimal delays in waiting for surgery and other treatments.	Stop treating cancer patients as 'elective' cases.
	Earlier/ quicker appointments with oncology after surgery.	Provide more staff and communicate about delays and help people deal with the stresses of waiting.

Experience-based surveys—Most respondents had a very positive experience while attending the hospital and greatly appreciated the efforts of staff to make their experience as positive as possible (Figure 2). Comments such as "excellent service" and "staff were great" were common. However, about one in 10 patients had a 'bad' or ‘very bad’ experience, and these made a big difference to the average rating of the service.

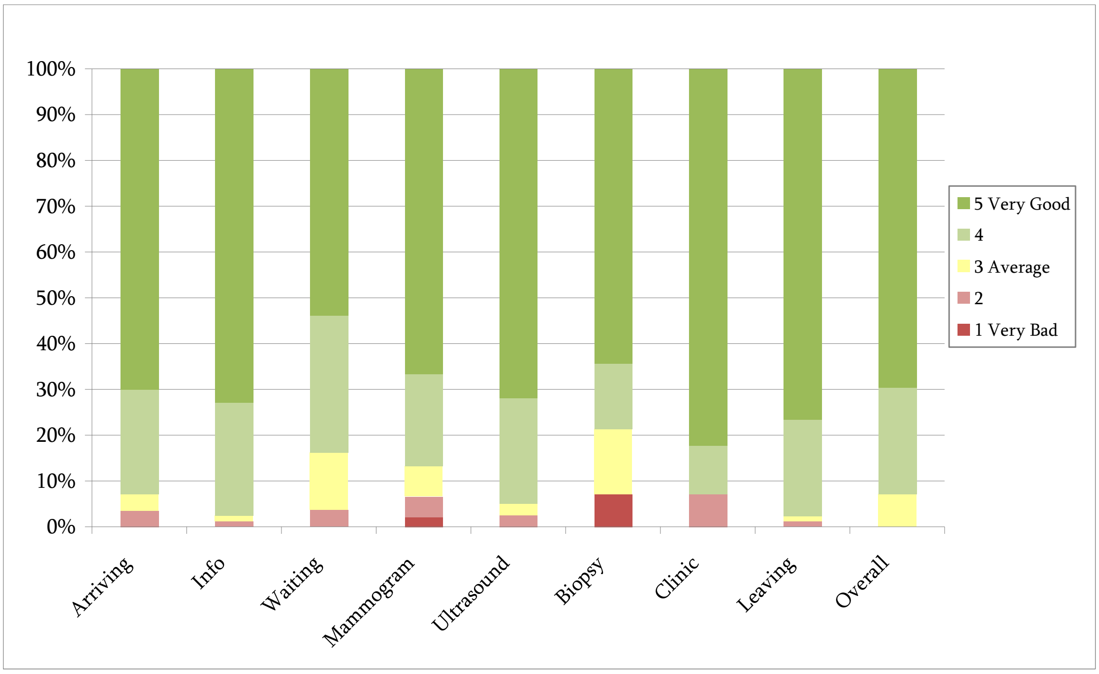
Most negative experiences arose through:

- Increasing anxiety while waiting at any time, especially if staff were uninformative (the bigger problem) or impolite.
- Anxiety and pain during mammography, biopsy and clinic appointments, especially if staff were uninformative, rough or impolite, or if patient expectations of pain were not actively managed.

Further suggestions made as to ways of improving the service included:

- Better-written information about what the appointments are for and what patients can expect when they attend.
- Improved facilities ranging from layout the waiting rooms through to design of mammography gowns.
- Better communication about likely pain levels and how to minimise them.
- A clear explanation at the end of appointments about what will happen next and when.

Figure 2. Patient ratings of journey experiences



Co-design workshops—At the start of their journey, patients wanted answers to ‘big picture’ questions to orient themselves to the news of their cancer and to gain a picture of how the Breast Service would be helping them. They wanted reliable, relevant facts about cancer and the Breast Service. Many were too shocked to take in detailed information and needed time to adjust to the news of cancer. At the start of treatment patients typically wanted information to help them understand what their possible future outcomes and their best treatment options were.

Recommendations focussed on ways of developing processes to improve communication, and included:

- Developing a staff communication guide for use by all clinical staff who have contact with patients
- Designing a patient held record
- Rationalising information given out within the DHB
- Developing a sectionalised/care diary.

Further workshops were held to develop these ideas.

Table 3. Key questions patients wanted answered during their breast cancer journey

- When will I know the radiology results? Who will tell me?
- What sort of breast cancer do I have?
- What is my prognosis?
- How bad is my cancer and what are the treatment options?
- Do I have to have treatment?
- What is my best treatment option? Why?
- How do I know that the treatment will be successful?
- Will I get sick with my cancer treatment?
- When will my appointment be?
- Is there a chance of the cancer coming back? How will I know? What can I do to lessen the chance?
- How long do I have to live? What should my priorities be?

Emerging themes for the Breast Service—Each of the three tools yielded different information that was then analysed to identify key themes. Specific improvements were prioritised during a co-design workshop. There were four emerging themes.

- The provision of timely, accessible information was a key issue. Equally important was a way of managing the vast array of information that breast patients received. Patients were keen that the information they received was streamlined and that tools, e.g., folders and hand held records, were developed to help them manage the information.

- The role of compassionate communication. It was important for patients that staff were able to communicate clearly and with compassion. Simple things such as smiling, introducing oneself and one's role, explaining concepts accurately and being clear about what would happen next were vital for patients. The ability of staff to understand the patient experience was seen as fundamental.
- The need for navigation and co-ordination. Patients wanted a person who could meet and greet them on arrival and help them navigate their way through the journey, both literally and metaphorically. There were various opinions as to who would be best suited to provide this role – patient buddies or a dedicated staff member – and the scope, i.e., whether it would extend to being a service co-ordination role.
- A desire for a pleasant, easily navigable physical environment. This encompassed a wide range of issues ranging from getting a car park and finding the clinic through to the layout of the clinic and the design of the mammography gown.

Changes made—As stated earlier, amongst other things the project aimed to implement small, focussed changes. The improvements we made are listed in Table 4.

Table 4. List of improvements

A map of the patient journey	A strategic tool for staff allowing them to see the experiences over time. Provides a framework for evolving current and future improvements.
Patient information folder	A folder of information to help patients navigate their way through the Service.
Patient leaflets	A suite of seven new patient information leaflets. Enabled local information to be included and a constancy of supply of leaflets.
Patient held record	A double-sided card for patients to track their appointments. (Useful for staff too.)
Patient journey guide	A high level visual map of the journey. Staff can use this with patients to explain their journey and where they are in the process.
Communication guide	A poster in cartoon format with tips for patients and staff on how to communicate better.
Mammography gown	A gown, specifically designed to address usability problems for patients and staff was developed.
Co-design toolkit	Development of a co-design toolkit and website for healthcare services. The toolkit has 18 tools matching six key project phases.[10]

Discussion

Implementing co-design in healthcare can be a challenging endeavour, especially when clinical workloads are high and the organisational environment is fiscally constrained. However, the benefits of co-design, both in terms of increased staff understanding of patients' experiences and improved experiences for patients, are potentially enormous.

Key learnings about the process:

- Use of co-design does not mean the abandonment of more standard, well-recognised quality improvement methodologies. Co-design can potentially work well alongside Lean and Six Sigma methods (which focus on more measurable areas of service improvement such as prioritisation, queuing and adherence to guidelines) as long as one method does not subsume the other.

- Engage with patients early. Engagement is absolutely critical to true and successful co-design. Having patents involved early means that their experiences and requirements can be taken into account at the *start* of the process rather than people presuming to know what is required.[2,3] In our project patients were invited to a workshop *before* decisions were made about its final scope and structure. Relationships with patients were developed and continued throughout the project to varying degrees. An important consideration was the acknowledgement that many patients were still receiving treatment during the project so energy levels and availability varied accordingly.
- Work hard to ensure a representative spread of patients. It is acknowledged that self-selecting patients may not be representative of the patient population more generally. Specific methods should be considered to target involvement across the patient spectrum.
- Staff buy-in is fundamental. Clinical, management and administrative staff are busy people, yet their involvement in co-design work is vital. Staff attendance at workshops with patients gives them a unique opportunity to understand patients' experiences in a different way. In a supportive, workshop environment where staff and patients are equal, patients will often open up and share their perspectives in a way they would never do in the clinic room. The success of co-design work then, is greatly enhanced through communication with staff and their active participation.
- Be prepared to try things outside your comfort zone. Many elements of co-design involved trying new things and that required faith in the process. Early on a workshop was held with a wide variety of stakeholders including medical staff, patients, people interested in innovation and improvement specialists from external industries. Having extensive input early on in the project provided a richness of ideas from which to build a strong foundation. Use of service design tools, such as emotional journey mapping, involved learning new ways of thinking and challenging existing ways in which things have been done.

Spreading the word—As a result of the success of the project, co-design has been used within Melanoma Services at Waitemata DHB and more recently looking at advance care planning at Auckland DHB.

While co-design work has not yet become widespread in New Zealand, there is certainly a real interest in the method. The Ministry of Health funded the development of a health co-design toolkit[10] and website www.healthcodesign.org.nz. Training sessions organised at Waitemata DHB proved popular, with a willingness and desire amongst staff to learn about and use co-design. In 2011, the Central Cancer Network facilitated a series of health service co-design workshops within their region, primarily aimed at a cancer control audience. The need for using a co-design approach to develop supportive care strategies for adults with cancer in New Zealand has also been recognised.[12]

With ongoing funding and support, co-design could spread to other DHBs and health services throughout New Zealand. The use of co-design could initially be targeted to high need areas. For example, it could have particular benefit for services where there has been a lot of staff dissatisfaction or patient complaints, where there are high DNA (Did Not Attend) rates or where a new service or facility is being developed.

Recommendations:

- A limitation of this work that planned evaluation was not able to be undertaken on the effectiveness of the improvements, i.e., what (measurable) positive difference did the improvement have on patients' experience of the service? We recommend that co-design projects factor in time and resources to allow an evaluation to take place after the improvements have been made and bedded down. Note that a co-design project identifies process and outcome criteria as part of designing improvements. These can then be used in evaluation work.
- Many organisations simply implement improvement initiatives without consideration of ongoing sustainability of their work. Organisations that are successful are the ones that can both implement and sustain improvement over time leading to increased quality and patient experience at lower cost. Co-design's emphasis on working with all stakeholders on an ongoing basis, and service users in particular, suggests it is implicitly more sustainable than conventional approaches. Further research in this area is recommended.
- The Patient Co-design of Breast Service Project not only made tangible improvements but it has demonstrated the potential value of engaging patients and focusing on their experiences. Although not formally evaluated, a limitation noted above, our work supports the findings of people who have adopted the method overseas: using co-design within the healthcare context is valuable and worthwhile. We recommend that DHBs and other health services in New Zealand recognise the value and benefits of co-design and consider adopting it as a key approach to service improvement.

Competing interests: None declared.

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(**Note:** Hilary Boyd, Bernie Mullin and Andrew Old all worked in the Healthcare Improvement Team at Waitemata District Health Board at the time this piece of work was undertaken.)

Acknowledgements: We thank all those involved in the Patient Co-design of Breast Service Project, in particular, all the patients who took part. Special thanks also go to Richard Harman, Surgeon and Clinical Leader for this project.

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Appendix 1. A map of the patient journey