

# Patient centered outcomes in brain health

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### Abstract

*Understanding the experience of patients and their whānau provides insight into health care as well as being a crucial step toward partnering with patients to drive improvement. This elevation in the conversation on the 'healthcare experience' resonates now more than ever. People are not just passive participants in a care transaction or simply recipients of care, rather they are partners in a care conversation, who must be acknowledged and cared for as people in a health care experience. Their voices, what matters to them and the expertise they bring, regardless of the side of the care equation they sit, must now be part of the overall solution. What was revealed in this work is the experience that people in healthcare have matters to them in significant ways. And in recognition of this Stroke will be a major healthcare driver nationally, now and into the future.*

### Introduction

To live up to the mantra of 'nothing about me, without me' in health care, we need to understand the current experience of patients and their whānau as well as partner with them to drive improvement in health care.

Listening to patient's experience and understanding is the first step. Taking the next step of engaging patients and whānau in improving care delivery is leading to a range of outcome benefits for healthcare organisations committed to a 'client focus'.

I've been working (part-time) as a Consumer Advisor for the National Stroke Network (NSN), Northern Regional Alliance (NRA) and Health Navigator since 2015, and the landscape has changed considerably in 5 years. When I started out patients advocating for their care was a relatively new concept. We have now moved from advocacy to patient and family activation.

All the terms used creates misunderstanding - "consumers", "patient- and family-centred care", "patient and family engagement", "patient experience", "people-centred care", and "lived experience" - many weren't really used 10 years ago. Now we have patient-whānau advisors working on quality improvement, and working in a very sophisticated capacity. We're making good progress in caring about the patient experience, and bringing in patient-whānau advisors and community members as partners.

We're doing a good job working with people as advisors, but we're still struggling to figure out how to partner with patients when they're actively sick.

### Distinction between "people-centred care" and "co-designed care"

I respect and believe in patient and whānau-centred care. However, can we technically decide what this means without a 'patient' in the room? In theory, we can be patient-centred by thinking about how we deliver care from a patient-centred perspective.

On the other hand, you can't co-design without a person (with lived experience), whānau, or community members as a part of the process. There is a big distinction. The co-design language is new enough that people use the term to mean different things.

In the way the project group I worked with practiced co-design, whether it was at the bedside or when working with people on policy, a person (with lived experience), whānau, or community was part of the process. We used a model that has been successfully implemented nationally called Experience-Based Co-design. It's a very structured process where issues are identified by speaking with people, patients' whānau, and community members.

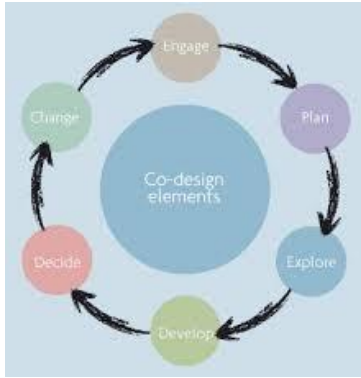


Figure 1. Healthcare Codesign  
[\(https://www.healthcodesign.org.nz/\)](https://www.healthcodesign.org.nz/)

Co-design means not coming in with assumptions. It means coming with an open mind and saying, “You tell us where we need to start. What is the most painful part of this process for you? What do we need to change?”.

This is in contrast to what we see with ‘consumer’-advisory councils. For example, where the staff come to the council assuming that they know what bothers ‘consumers’ or what matters most to them: “We already know what the problem is. Now we want you to tell us what to do about it.” When we start with our assumptions, we may or may not hit on the most important or meaningful issues for patients.

Taking this approach can result present requests.

That’s the beauty of it. And there may be requests, but there are often simple solutions to those requests. The key priorities that patients and whānau typically describe tend to be things that aren’t outside the box. Some real examples include things like hanging clocks in ED rooms, re-designing welcome booklets, and changing the time housekeepers empty trash containers on the unit. None of these are very costly or dramatic changes, but patients and whānau have said they mattered. It’s also very likely that ideas like these wouldn’t be identified or implemented without the co-design process.

### Case Study:

#### Stroke Hyper Acute Process - First Phase

In June 2015, a proposal was endorsed by the Regional Governance Group, to develop a high level plan to develop a regional approach to hyperacute stroke care. There are two principle reasons for developing the regional hyperacute pathway:

1. The first was related to the international results of a series of clot retrieval studies and, as Auckland City Hospital (ACH) had participated in one of these studies, it already had some capacity to provide a service. The concern had been that ACH did not have capacity to provide a full 24-hour service and there was an imperative to develop a plan to manage what was expected to be an increasing referral demand. In addition to this, it was clear that volumes of referrals would be low and therefore effectiveness of a 24-hour service would be compromised unless thrombolysis rates increase (patients must have had thrombolysis to be eligible for clot retrieval).
2. Northern Region thrombolysis rates fell well below international best practice standards and with substantial improvement, not only patients who underwent clot retrieval would significantly benefit but also those who were treated with thrombolysis.

**By improving our services to meet world’s best standards, we believe that up to an additional 100 people each year could be free of significant disability after stroke.** Improved hyperacute pathway processes could deliver two thirds of that gain.

## **Stroke Hyper Acute Process - Second Phase**

Undertaken to capture patients' experience of care during the second phase of the Northern Region hyperacute stroke pathway and clot retrieval service implementation at Auckland City Hospital.

The Northern Region implemented the first phase of the regional afterhours hyper acute stroke pathway in August 2017 with patients living in the Waitakere Hospital catchment. This meant that anyone in West Auckland who had a stroke afterhours i.e. after 4pm on a week day, all weekend and public holidays, were diverted to Auckland City Hospital instead of Waitakere Hospital.

The second phase, which commenced on 3 September 2018, extended the afterhours hyperacute stroke service to all people living in the metro-Auckland area. The second phase concluded on the 31 August 2019 having seen a total of 133 diversions and a total of 230 percutaneous stroke interventions (or stroke clot retrieval) in the 12 months that it ran.

## **Scope**

The scope of patient interviews was to get an understanding of how patients who had a stroke afterhours, experienced their care from the moment of symptom onset, their diversion or transfer to Auckland City Hospital for treatment, treatment/intervention at Auckland City Hospital, their transfer back to their local hospital, and the post intervention care at their local hospital.

The scope also extended to stroke patients who were transferred to Auckland City Hospital for percutaneous stroke intervention (PSI). These patients could be transferred at any time of the day as the PSI service operates 24/7 out of Auckland City Hospital.

Patient experience of their stroke rehabilitation was not in scope for these interviews although in many cases, interviewees did touch on aspects of their transition back to home, ongoing recovery and rehabilitation.

## **Findings from Patient Experience of Care Interviews**

The experiences reported by patients or their carers identified 5 touchpoints in their care on the hyper acute stroke pathway. A touchpoint is any point of contact patients have with the service and is regarded as a key moment that shapes a person's overall experience.

## **Regional Hyperacute Stroke Pathway Touchpoints**

The power of consumer narratives and stories, and the opportunity to include patients and their whānau as partners in decision making provided the opportunity to consider what truly mattered for consumers experiencing stroke.

Listening to patient narrative stories about their experiences provided insight into expectations of care, in a manner that healthcare professionals found interesting.

Ultimately, at the centre of really understanding patient values and preferences is establishing a relationship between clinicians, patients and patients' whānau grounded in strong communication and trust.

Many aspects go into making patient initiatives successful. Whether through training staff or including new technologies, each approach requires organisational commitment to work effectively. Patient initiatives start with involving patients and their whānau to understand what makes them sick, what they need to stay healthy, and what they would like to do if their conditions get worse. It means motivating and empowering patients to work with clinicians - to be active participants in their care by asking questions, knowing their medications and medical history, bringing friends or relatives to appointments for support, and learning about care that may be unnecessary.

To be successful during an era of changing health reform, providers must give patients consistent messages about how to manage their care at all touch points. Providers have the opportunity to create two-way communications that are consistent and personalised to the needs of the individual and the specific point of interaction in their care. Patient stories which span an entire continuum of care are useful in identifying the many ways that patients interact

and how issues outside of their care management, i.e. psychosocial, financial, impact how and when they choose to interact with the system.

Patient experience fits into the overall healthcare picture more today than it ever has. As population health management, accountable care and healthcare reform mature, the efficacy of those efforts will depend more and more on how well providers can integrate the design of patient experience and empowerment into the expanding care continuum.

Given the pressures and constraints that so many clinicians face, how can they build a trusting relationship with patients when they often have so little time with them?

We have to activate our patients. Activated patients who are able to take some responsibility for their health and health care can help take some of the burden off of those delivering the care. As we continue work at involving patients and families and improving patient experience, we also have to help those patients and families become more involved members of the health care team.

The ideal experience was grounded in caring, professional and helpful encounters. These positive experiences have significant consequences for healthcare

### **Recommendations for Improvement**

The following recommendations have been made based on the information gathered from interviews.

#### **People**

##### ***Communication and trust***

- All communication - verbal and non-verbal - must be done in a manner which is respectful, kind, compassionate, inclusive, professional and culturally sensitive.

#### **Process**

- Explanation should be given by ambulance staff to all patients and their families/ whānau as to why they are being transferred to Auckland City Hospital instead of their local hospital for treatment.
- All delayed transfers back to patients' home DHB should be communicated by Auckland City Hospital staff to patients and carers, and reasons for delay given. Communicate what is going well and also what isn't going so well.
- Review transfer pathways between Auckland City Hospital, St John and the different DHBs regularly.
- Inform patients and their families/whānau if the expectation is that they will be charged for the ambulance trip back to patients' home.
- Consider if patients in recovery should be transferred back to their local DHB in the early hours of the morning (between 12am and 7am).
- Reasons for delayed admission to the stroke unit should be investigated to understand the root cause and improved upon.
- Before discharge, patients should be briefed on the reason for their stroke and what might have caused it and what they can do to prevent its occurrence.

#### **Place**

- Monitor and reduce overcrowding in treatment and shared recovery areas as it can be disconcerting for patients.
- Monitor noise levels on the stroke wards to ensure that patients in recovery are not disturbed by other patients or their visitors.

#### **Additional Observations**

These are not strictly in the scope of the hyperacute stroke pathway interview but were raised by patients and/or their carers in the course of the interview.

- **Availability of more intensive community OT/ PT/ SLT**

Patients indicated they wanted to receive more intensive rehabilitation in the community

- **Rehabilitation to include supporting emotional needs**

Patient talked about their “rehabilitation” as activities centred around physical therapy received for restoring functions like – walking, talking, strength, speech. But there were other issues which were raised including:

- Anxiety about recurrence of stroke
- Wanting information around the effects of the disease on sex and intimacy post-stroke
- Anxiety around driving

- **Rehabilitation closer to home**

Patients indicated a preference to be rehabilitated closer to home due to reasons including convenience for families to visit, parking challenges at the Auckland rehabilitation site.

- **Support for carers to be a part of patients’ rehabilitation**

Some spouses acknowledged they were finding it difficult coping with the changes to their partners.

### **Closing thoughts from the regional stroke consumer lead**

Healthcare organisations say they should be patient-centric or provide empathy and compassion, but what patients want are the tangible actions that exemplify those practices. While being listened to is a means of expressing empathy and compassion, patients don’t want healthcare providers to say they are compassionate, they want healthcare providers to listen and act.

A consumer’s experience is important to them; it is about being *acknowledged and engaged* in the healthcare process. How people are treated matters.

The need for *open and clear communication*, courteous and respectful treatment reinforces that to consumers, it is how they are engaged and treated in healthcare that matters.

The most important factor in having a good experience for consumers was the importance of being listened to. This reinforces how consumers see themselves as active partners in the healthcare process that they have something to say and to contribute and a voice that desires to be heard AND acted on.

The ideal experience was grounded in caring, professional and helpful encounters. These positive experiences have significant consequences for healthcare.

While efforts have been established to tackle the divisions of care delivery in healthcare, the consumer sees it all as one experience and so healthcare organisations need to consider how they address care in a continuous way.

### **Suggested reading**

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