**Exploring how the way we work impacts the consumer experience**

**Accessible transcript**

Audio

(RELAXED MUSIC) (MUSIC FADES). What is going on when things don't go well? An exploration of consumer experiences of communication and decision-making when things do not go well and a clinician's perspective of what might be contributing to that experience. A disclaimer before we start — the Commission's advance care planning and shared goals of care teams sought to understand the lived experience of clinical discussions from a group of consumers and clinicians, including doctors and nurses. The purpose was to identify opportunities to improve the experience of shared decision-making for both the consumers and the clinicians. This presentation and the infographics it discusses were created by an illustrator who worked with the Commission's advance care planning and shared goals of care teams. They reflect the experiences, views, ideas and thoughts of this group and are not intended to represent all views and perspectives. The Commission's advance care planning and shared goals of care teams had worked with an infographic storyteller during the development of the talkingCOVID website and had found this was an authentic way to capture lived experience. We wanted to develop a similar infographic to capture the consumer and clinicians' experiences of communication and decision-making in health. So we engaged several times with a group of consumers over Zoom, and they shared their experiences of communication and decision-making in health. There were nine women, three of whom identified as Māori. They were of various ages, and the stories they shared covered personal and whānau stories from both rural and urban settings across primary and secondary care. Our illustrator captured the essence of what was shared in a series of iterations. We heard about experiences of when things did go well — what made them positive experiences. We also heard about when things didn't go well and the long-held emotional pain associated with these latter experiences. Common themes from the stories about when things didn't go well started to emerge. We felt that these might inform how we could improve decision-making and were really valued for the emotional insights they provided.

**Visual**

**Black text on a white screen reads ‘What is going on when things don’t go well?’.** **In the top right corner is a logo which reads ‘Health Quality & Safety Commission New Zealand Kupu Taurangi Hauora o Aotearoa’. The blue and green company logo comprises of three thin square blocks with white circles of differing sizes within them. In the bottom left corner is a logo which reads ‘our voice tō tātou reo, advance care planning’.**

Audio

The kūmara vine was a storytelling platform that emerged from the first meeting of consumers — through the telling of a story about how the kūmara vine or the 'gossip telegraph' was very quick to share the bad experiences, to warn and advise others in the community about, you know, which health care provider to avoid or to be wary of. We heard many good experiences — the polar opposite of the experiences we are about to share — where consumers felt included, empowered, informed, listened to and heard. These stories give us hope that the system can and does work a lot of the time. We need to figure out how to do less of what negatively impacts and more of what enhances the health experiences and outcomes for consumers and their whānau. We acknowledge that it can be hard to hear the lived experience when it reflects the opposite of how we want consumers to experience care and that the next couple of slides you may find unsettling. However, in order to improve, we do need to be authentic and open to listen.

**Visual**

**An illustration appears on a white screen. The heading reads ‘Experiences of healthcare when things don’t go well’. Beneath the heading is a drawing of a kūmara vine on the left and on the right is four squiggly lines, depicting vital signs. The heading above reads ‘Clinician’s experiences’.**

Audio

The consumers shared stories about bias, racism and the power imbalance; when the small things taint everything else that comes before and after; not being invited to contribute; ignored when they did; disregarded; not heard; not respected; labelled; being given information in a way that hurts and harms; finding the complex information overwhelming; the indignity of lack of privacy and looming clinicians; bluntness; being patronised and spoken down to; feeling alone; and being offered treatments they recognise they never actually received. Our illustrator reflects these emotions in the colours and leaves of the kūmara vine. So, why is the kūmara vine of consumer experiences browning and losing leaves? It's browning and losing its leaves to represent the things in the system that negatively impact consumers' ability or willingness to participate in decision-making and the impact of that on their quality of life and access. The reason the group still wanted to keep strong green vines between the dying leaves was to represent that there are also many good experiences and to pose the question — how might our stories improve things? Let's unpack this more and see what the common themes were.

**Visual**

**An illustration appears on a white screen. The heading reads ‘An overview of consumer stories, experiences of healthcare when things don’t go well’. The illustration shows a green vine which weaves its way around the screen. The vine is browning in parts. There are words and illustrations of people dotted along the vine, highlighting the main issues experienced by consumers when things don’t go well.**

Audio

There were four pervasive themes that were consistently threaded through the stories, so we captured them as mainstays of the kūmara vine. It's the small things. The tone of voice, attention, kindness and comfort offered by all staff are key to good experiences. However, when these things are lacking, it significantly impacts the level of confidence, trust and safety experienced by consumers. It impacts their willingness and ability to engage and, as a consequence, their willingness to share what is important — you know, their hopes, values and aspirations. Bias. The bias and racism that was shared was harrowing, and it upset some of the consumer group that had not experienced it personally. Māori and Pacific consumers and their whānau were disregarded, ignored, spoken down to, patronised, labelled and marginalised. One participant shared her experience of a pretty impressive health care service she received that was completely tainted by one clinician who disparagingly remarked, 'You Māoris.' Bias blinkers clinicians and results in issues being ignored or assumptions being made. For example, a consumer whose mother was pigeonholed for her known mental health issues — her acute medical needs were completely ignored, and her care was compromised as a consequence. This concept of how a bad experience can taint all other experiences was described like a glass of clear water that has a drop of ink added to it. It will always be tainted by that ink, or bad experience. Regardless of how many good experiences dilute that over time, it'll always be there, even at a microscopic level. The power imbalance that's inherent in the health care system, again, was another salient theme. The all-knowing and powerful clinicians who hold people's lives in their hands — you know, that whole paternalistic lens — and the consumers who have to take it as it comes, worried for themselves and their whānau, afraid to speak up, and how — if they do — it may influence the care they receive, unable to take the issues elsewhere or fix them themselves, caught between a rock and a hard place.

**Visual**

**A small section of the kumara vine illustration appears on screen with a white background. The heading reads ‘An overview of consumer stories, experiences of healthcare when things don’t go well’.**

Audio

As we continue to explore the other themes that emerged, it's essential to remember that these themes that I've just described underpin and weave themselves through all of them in one form or another.

**Visual**

**The original large kumara vine illustration appears on the screen on a white background.**

Audio

Let's build on the idea of being powerless, voiceless in the system. Consumers were really confident about their insight and expertise into their own and their whānau's health and bodies — for example, relating how current symptoms just don't seem to be stacking up, or the best way to get in a line following multiple admissions. They spend all their time away from this health care moment or intervention, living their lives with their bodies and minds, and they bring that experience and knowledge to the system. Unfortunately, they related that this expertise is not drawn on; it's ignored, or worse — discouraged. When they did speak up or push back, they felt labelled for that. They also felt labelled as complacent or disengaged if they didn't speak up. Consumers know the system labels them, and it shuts them down for the fear of this, sort of, perceived effects of a label on their access, or worse — their quality of care. Some of the stories related feeling really confused by the amount and complexity of information that they were being provided with or the way the information was shared that left some feeling embarrassed or anxious about asking for clarity. Many of the stories highlighted inequality, perpetuated through, you know, the quality of services provided, the geographical location of services and/or the way clinicians communicated or listened or failed to listen.

**Visual**

**Another small section of the kumara vine illustration appears on screen with a white background. The heading reads ‘An overview of consumer stories, experiences of healthcare when things don’t go well’. As the speaker talks, different parts of the illustration are highlighted.**

Audio

Most of the stories included reference to feeling unheard or not being listened to, not being acknowledged, not being asked, being spoken about instead of to. This meant that the decisions that were subsequently made had some long-term negative impacts on consumers' willingness to engage with the system — a sense of increased distrust, disempowerment — and the consequences and outcomes that potentially reduced their life expectancy and/or reduced their quality of life, increased their vulnerability.

**Visual**

**Another small section of the kumara vine illustration appears on screen with a white background. The heading reads ‘An overview of consumer stories, experiences of healthcare when things don’t go well’. This section is titled ‘not listening’. As the speaker talks, different parts of the illustration appear on screen.**

Audio

Consumers felt vulnerable in the system — lying in a bed out of their familiar environment, exposed by shared spaces, altered states due to medication, often alone. The idea of the looming clinician emerged — so, standing over the vulnerable patient with an entourage of students and others looking on. One consumer implored, 'Please, just ask before you bring along all those students.' There were some stories where the diagnosis or prognosis was shared in an unemotional and hard way, or shared with the person at a time and place and in a way that was harmful. The pain of that moment was tangible many years later.

**Visual**

**Another small section of the kumara vine illustration appears on screen with a white background. The heading reads ‘An overview of consumer stories, experiences of healthcare when things don’t go well’. This section is titled ‘patient vulnerability’. As the speaker talks, different parts of the illustration appear on screen.**

Audio

There was frustration with the way treatment options were discussed — either that the clinician mentioned treatments that they weren't going to be offering or discussing all of the options in a way that made it clear that they were not really options, as the clinician had already decided what they were going to do. The 'should I ask' lottery.

**Visual**

**Another small section of the kumara vine illustration appears on screen with a white background. The heading reads ‘An overview of consumer stories, experiences of healthcare when things don’t go well’. This section is titled ‘offering treatment options’. As the speaker talks, different parts of the illustration appear on screen.**

Audio

So, this captures what we've already spoken about — that fear and/or embarrassment about asking questions, feelings of being shut down or labelled or feeling foolish. We want to reiterate that we heard many good experiences too, the polar opposite of these experiences, where consumers felt included, empowered, informed, listened to and heard. Those stories give us hope that the system can and does work a lot of the time.

**Visual**

**The original large kumara vine illustration appears on the screen on a white background.**

Audio

So, how is it for clinicians in the system? We shared the consumer experiences infographic with a group of clinicians, clinicians in practice and those that lead or work within the advance care planning, shared goals of care and mortality review committee programmes at the Commission. We asked them what they thought might be contributing to these consumer experiences or impacting on decision-making.

**Visual**

**An illustration appears on a white screen. The heading reads ‘Experiences of healthcare when things don’t go well’. Beneath the heading is a drawing of a kūmara vine on the left and on the right is four squiggly lines, depicting vital signs. The heading above reads ‘Clinician’s experiences’.**

Audio

What emerged is a tangle of a system — process, professional and personal complexity — a reflection of the complex adaptive health system within which we work and includes organisational and team culture, clinicians' skills and experience, management practices, systems and processes, the way work is organised and the constraints of the physical environment. The illustrator and project team felt a tension in how to simply capture something so complex in order to make it a usable storytelling tool and, at the same time, not dilute the reality of the web or tangle of the various parts of the issue. When we did eventually agree with the storytelling mechanism of a group of vital sign monitor readings, and before the illustrator created the, sort of, tangle of all the monitor cables here on the right, someone had commented, 'Ah, it looks like four improvement projects — nice and neat.' (CHUCKLES) If only it were that simple, we could just fix it, right? The imagery of the vital signs monitor readings represents the many different interlinking systems and processes of a complex, adaptive system — demands coming at you from all directions. But it's also simple enough to enable us to try and understand the experience. Note — these are not in a hierarchy. So, let's look at each, starting with attitudes and culture.

**Visual**

**A complex illustration appears on screen on a white background. The heading reads ‘Clinicians’ experiences, experiences of healthcare when things don’t go well’. A set of four lines cross the screen, depicting vital signs. Across each line is a series of illustrations showing clinicians’ experiences in four areas. The first line is titled ‘Management & leadership’, the second line is titled ‘System’, the third line is titled ‘Clinician skills & confidence’ and the fourth line is titled ‘Attitude & sector culture’.**

Audio

We heard that for some clinicians, large whānau groups were daunting. There was fear that conflict would arise and they would not be able or feel confident to manage it. For some, it sounded like a lack of confidence in being able to predict what might happen if the family wanted to know. There was a fear of getting it wrong, saying something that would upset the family or the patient, so better to avoid the conversation altogether. So, for example, one clinician said, 'To take patients and family through your thinking, 'how you have got to where you are with your thinking, 'leaving the door open to the possibility 'that you might not have it right — 'all that takes skill, experience and practice.' Yes, we do sometimes label patients and whānau, making judgements about the person and/or whānau that is then captured in the record and then colours everyone's views and impacts — the 'difficult patient' or the 'stroppy mother'. Why do we do this? Some thoughts were maybe clinicians are protecting themselves or warning the next clinician, like a safety intention or time-saving. Labelling might be a coping mechanism. For example — 'I can't do this.' 'I'm overwhelmed.' 'It's their fault.' 'They're making it harder.' This might be explicit, or it might be in body language, like sighing or being very busy or being dismissive. This might be about the patient or the whānau not listening to the clinician when the clinician has already explained it, or about not having the skills to deal with the challenge.

**Visual**

**The fourth line of the vital signs illustration appears alone on screen on a white background. The heading on the right reads ‘Clinician skills & confidence’. As the narrator talks, illustrations appear along its length, highlighting the key issues experienced in this area.**

Audio

There was lots of discussion about how clinicians' skills and confidence might be impacting. Some clinicians have very specialised clinical knowledge and only consider a part of the consumer rather than the whole person, the whole mind and body. So if a patient is under more than one team, the patient might be referred to another team to get their question answered, because it's not about the organ or system that this clinician is dealing with. Or each team assumes that the patient's getting info from other teams. This is confusing for the patient to know which team or clinician to ask. This can also mean that the person gets many different perspectives or views from different clinicians, which sort of compounds the confusion. Too busy. In a busy health care system, clinicians are constantly being pulled in all directions. There's a rush, time constraints, multiple competing demands. It's a matter of prioritising, so how do clinicians determine the most appropriate use of their time? And maybe having a difficult conversation just doesn't bubble to the top of their priority list. There is a lack of confidence in talking to patients and whānau, so, the fear of making mistakes or upsetting people, being unsure of the culturally appropriate way to communicate and include whānau, fear of being judged by your superiors or your peers. These competing demands and, you know, those clashing priorities. One clinician said, 'I don't want to say the wrong thing, raise expectations. 'I don't know the answer, and I'm worried that 'they're going to push me and then I'm going to have to say something 'that will mislead them.' There's also anxiety about causing harm, especially when thinking about sharing bad news. The interaction, the hearing of a prognosis or diagnosis is a new and unique experience for the consumer. But for lots of clinicians, this interaction is the same as the one before and the one that will follow. It becomes routine and mechanical. Skills and confidence also impact on how treatment options are explored — not having the skills and confidence to know what the most appropriate treatment is or how to say what won't be offered, or explore first what matters to the person and then tailor recommendations to match that. One clinician said, 'It's a tricky balancing act. We should share what we know. 'If we filter information, 'then the next clinician shares something you held back. 'That then puts you in a precarious position about not being open.' Lots influencing this — you know, it backfires if you do, and it backfires if you don't.

**Visual**

**The third line of the vital signs illustration appears alone on screen on a white background. The heading on the right reads ‘Clinician skills & confidence’. As the narrator talks, illustrations appear along its length, highlighting the key issues experienced in this area.**

There are complex and numerous processes which create information overwhelm. Some clinicians might not know how to chunk information and ensure the patient understands. We are familiar with our world — the hospital, the clinic, etc — but consumers are not. We might forget this and use language that would only be able to be understood by someone else who also knows the system, and we assume existing knowledge or pre-existing knowledge. As a clinician, it looks straightforward, but for the consumer, it feels like a foreign language. To be truly present with a person can be difficult — pager going off, mobile phone beeping, interruptions, the next 10 tasks in the clinician's head. All of this means that potentially the clinician is not fully present and would then not be open to listen and give the person focus. An example shared — 'The surgeon was sitting 'on the edge of the bed without introducing himself. 'He got a call from theatre and says, "Oh, don't start without me. "I'm on my way.' How does that leave the patient and whānau feeling about how focused that surgeon was on them? 'This is not my job.' 'Is it my job?' 'Should I have this conversation?' 'Will I get into trouble for having this conversation?' 'I can't start the conversation unless I get permission' — often heard from nurses and house officers, not recognising that clinicians can get support to have conversations from their colleagues. This highlights a culture in health care that each health care worker should be able to perform their role without leaning on others. Working in silos exacerbates this — silos within teams, across teams and across large sections of the sector. Patients assume that the system is connected and that everyone in the system is talking to everyone else, so when someone in part of the system hasn't heard about what the patient told someone else in the system, a patient feels like the first person didn't hear them or didn't listen, as opposed to a breakdown in the system. The pressure to deliver on tasks gets in the way. Like, for nurses, needing to get through medication rounds might mean that they don't dedicate time to sit with patients and whānau to listen. Big workloads, limited resources increase the impact of this — you know, there's not enough staff; there's not enough cover; needing to work long hours; fatigue. The division of labour is also a problem. You know, when time is limited, the best way to get through work is to be task-focused, which is not conducive to being relationship- or person-focused. Shift changes and a lack of continuity of staff impacts — you know, 'someone else will have the conversation', 'leave it for the next shift', or something significant learnt in this shift isn't handed over to the next one, leaving the patient and whānau feeling ignored and unheard. All of these pressures and systemic issues can also mean that if whānau are not present and this is the only time the clinician has to talk to the person, then the clinician pushes on, and the person is on their own during the discussion.

**Visual**

**The second line of the vital signs illustration appears alone on screen on a white background. The heading on the right reads ‘’System’. As the narrator talks, illustrations appear along its length, highlighting the key issues experienced in this area.**

And lastly — how does health care management and leadership impact the consumer experiences of decision-making? There was a sense that senior management expectations were adding pressure on the front line, that what they believe clinicians are doing might be quite different to what is actually happening. There's a lack of dignity due to the physical environment not having conducive physical space — sometimes something as simple as finding a chair to sit down and talk with the person. That can be really hard, and this contributes to the idea of the looming clinician.

**Visual**

**The first line of the vital signs illustration appears alone on screen on a white background. The heading on the right reads ‘’Management & Leadership’. As the narrator talks, illustrations appear along its length, highlighting the key issues experienced in this area.**

Audio

The experiences we have shared today from consumers and clinicians are not excuses, but they are a call to action to make the system better for everyone. They provide us with a picture or a story to help us consider the multiple factors that negatively impact on consumer experiences and the subsequent outcomes. They reinforce the need to take a systems approach to improvement. Educating clinicians is only one small step in the right direction. We also need to prioritise shared decision-making. Rather than talking at or to a patient and their whānau, we talk with them and let their priorities guide decision-making. Incentivise the right behaviours. Create the time, place and space. Clarify roles and responsibilities and support each other. So, what next? What's our call to action? Hector reminded us that when you know better, you do better. This complex tangle requires a systems design approach and the collective efforts of every single one of us in the system. We recognise that tangles will always happen in complex, adaptive health systems. It is how we work together that will change this. Together, we can change this.

**Visual**

**An illustration appears on a white screen. The heading reads ‘Experiences of healthcare when things don’t go well’. Beneath the heading is a drawing of a kūmara vine on the left and on the right is four squiggly lines, depicting vital signs. The heading above reads ‘Clinician’s experiences’.**

Audio

(RELAXED MUSIC)