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Thank you very much for the warm introduction.

I'm coming today from the West Coast of North America on the Pacific Ocean, and I'd like to acknowledge the First Nations, on whose land I'm privileged to work, live and continually learn.

It's the traditional, ancestral and unceded territory of the Muskingum, Suquamish and Tsleil-Waututh Nations of the Coast Salish people.

And I humbly express my gratitude to them and their ancestors.

My talk today is entitled Discovering Resilience from Patient Harm to Partnership. And thank you very much for attending.

First, to continue the identification, I call myself a citizen-patient. And what I mean by that is that I'm self-selected in this role. I have the perspective of both the citizen and the patient; that is both the dependent on our health care system and the funder of the public health care system. I view my work as an act of citizenship. I became involved because I passionately want to live in a society that affords all members with great health care.

Now, there are a lot of words for this kind of role in different communities around the planet. I know in New Zealand and in Australia ‘consumer’ is commonly used. In the Nordic countries, ‘next of kin’ is common. In Canada, increasingly, we use the word ‘partner’ to kind of indicate a more equal relationship in power. And I'm quite taken and passionate about my interest in whānau, what you in New Zealand have done to use Māori understanding and knowledge to really better understand the way health care systems ought to work. ‘Service user’ is oftentimes used in mental health, as is ‘client’. So, I think you can recognise many of the labels that we do this work with.

These are the perspectives that I'd like to share with you today. Now, there are lots of other titles that I carry for all the different kinds of activities I do. And, if there's time at the end of the talk, I'd be happy to talk about some of these roles that I have. So, I'll come back to this later.

But just one further thing about being an adjunct professor, I have no advanced education in health care. I came into this role 14 years ago at the time my husband died, unfortunately, only eight days after successful surgery. And I'll explain a bit more about that. So, my path has come from the lived experience and from doing my own work to better understand health care. I have no financial disclosures and no conflicts of interest for this talk. In fact, most of the work I do is voluntary, so, there is no financial factor.

So, the big idea of this talk is that we can learn a way of approaching safer care by mobilising curiosity and building trust. And that creates better outcomes for all, including better outcomes for health care workers.

I want to explain today a little bit about my personal path, my struggle as a harm survivor and following my own curiosity and discovering resilient approaches to a basic understanding for building partnerships of trust within the health care system. But there's also a parallel story about how a systems approach to patient safety is linked with partnerships that gain resilient capacity.

So, the takeaways that I offer today are the same takeaways that I spoke about last November, where some of you may have heard me. First, health care is a collaboration. It's not a service. You can't deliver health care. It's an activity. It's not a product; it's doing. And it's doing care.

Health care is defined by relationships of trust. And finally, improving care must then mean improving relationships. So, that's my orientation to what safer care and higher quality care are all about.

In some ways, I'm thinking about my presentation today as being a warm-up act for my dear friend Carl Horsley, who in two weeks will be giving you a presentation on resilience in the New Zealand setting.

So, I'd like to introduce you to my sweet husband Nick Francis. He's on the left-hand side of this page, and on the right-hand side is a famous train wreck in Paris 120 years ago. So, Nick died only eight days after successful surgery on his leg, as I mentioned. He was found non-responsive at 4 o'clock in the morning by a lab technician who was vainly trying to draw blood once again. There was a single nurse on night shift who realised her patient was crashing, but she was following doctor's orders for blood work. Well, finding Nick expired devastated his bedside carers.

When the day shift came on, the nurses were convulsed in tears. And I tried to console them. Nick was 20 years older than me, and we'd been together for 35 fabulous years. Because of that, over those 35 years, we had talked about the likelihood I'd outlive him. So, although the timing wasn't quite what I expected, I did feel that I was more prepared, apparently, than these nurses were, and I was really quite surprised that they were so moved.

When I thanked the physicians on their skill and their excellence in the operating room, because the surgery on his leg was so successful, one of them turned to me and said, ‘So what?’, and he was off to another full day in the operating room.

Nick had developed common post-operative symptoms, and those symptoms had been matched to the appropriate specialists to see Nick in a snapshot of care. But there was no physician, there was no technician, there was no clinician who followed Nick through his experience in those eight days.

So, there was no moving picture to see Nick deteriorate in a cascade to this calamity, to this unexpected death. I would say that Nick died of a failing model of care; it was fragmented care; it was siloed care. No one saw the whole patient over time. As his condition deteriorated, no one recognised his need for rescue.

OK, so that's Nick. That's one of the calamities on the screen. What about the other one? What about the train wreck?

Well, in this case, the train was running behind schedule. And the engineer increased the speed over the speed limit as he came into Paris. He was relying on the safety brake. Well, the brake failed, and the locomotive crashed through the station, and the falling masonry, as the locomotive fell down to the plaza out in front of Gare Montparnasse, killed one person, a newspaper vendor who was down below the station.

So, in each of these pictures, one person died. Now, this is another picture of the locomotive wreck. And you can see that there are workmen trying to stabilise the engine. There are what looks like administrators and business people standing around taking stock of what's happened. There are policemen. And in the distance, there's some Paris firefighters.

So, I wonder, the scene that they appreciated in this moment, how that's different from Nick's death. Unlike the train wreck, Nick's death did not attract attention. It was not named as an adverse event, although it was an unexpected death. Stuff happens.

This was easily ignored, so there was no case review and no follow-up. In the case of the locomotive, there was an investigation. There was an inquiry; and gaps were identified and fixed; compensation was given to the vendor's children for their education; and, in fact, that event changed practice. So, in Nick's case, although the surgeon who was, in fact, the quality improvement lead in that region of the health authority, did not choose Nick's case for M&M rounds (for morbidity and mortality rounds) because nothing went wrong in the operating room.

As the most responsible physician, he never read the autopsy report and, in fact, recorded the wrong cause of death on the discharge summary. He simply viewed this as the unfortunate consequence of risk. Well, this attitude, this lack of curiosity really didn't meet my expectations.

I was shocked; I was shocked at the way Nick's nurses had been abandoned; I was shocked at how traumatic the experience was for the physicians that morning; and I was shocked at the lack of any kind of follow-up, including follow-up for me.

So, I was kind of left on an empty stage. I found myself the only one to be asking questions. And this did not meet my mental model of what medicine was all about. The people I knew who had gone into medicine had prepared with extraordinary drive for excellence. So, they were the students who were in the lab till late at night getting straight As. They were the ones who demonstrated such a dedication to excellence.

And now here I saw that this environment of medicine had lost that ambition to learn, that curiosity. And it seemed so cruel for the workers and for the clinicians.

Well, I tried to put the pieces together.

I tried to learn myself what had happened. I got a copy of the chart; I went through it; and it was not easy to understand. I got help from some of our friends who wanted to know why their friend Nick had died – and these were people who were in nursing and retired doctors. It still wasn't at all clear.

The language that I encountered as I dug deeper into some of Nick's complications and some of the evidence that was in the chart, the words didn't mean what I thought they meant. And I didn't see anything in the patient safety discussions that matched anything like what I had observed.

In Nick's case, there was no error; there was no incident; there was no event; but there was rather a whole system of siloes that had contributed. And many of the words had definitions that did not make sense to me.

So, here's an example, ‘safety’. I hunted for a definition of ‘patient safety’, and the best one I found that seemed to be regularly referenced was ‘safety is the absence of harm’. And I thought, how can you study the absence of something? This doesn't make sense to me.

So, I decided, after about a year and a half, I was turning 60, and I thought, so how am I going to use the rest of my time? My life has been turned upside down with the death of my partner. Do I have the courage to see if I can do something? And I decided I would.

One of the images that I saw often in health care as I investigated it and investigated the area of patient safety was this metaphor of the iceberg. And when I thought about patient safety from my experience, it seemed to me that this was really the way the iceberg works – that above the waterline, you can see patient safety – patient safety is evident in the literature; it's evident in operations, in clinical practice – but the great unknown of patient harm lies below the surface.

And I found almost nothing investigating, describing, trying to understand the experience of harm. The experience of harm to the patient and their family and the experience of patient harm as it affects clinicians.

So, I thought, well, I guess this is the time I've got to decide. So, I decided I would dive deep, and I would explore this undescribed world. I needed to understand it for myself. I wanted to learn.

So, this is where I began to see something more than what I was reading about in the literature. It seemed to me, when a terrible event happens, that terrible tragedy has the very high likelihood if not the certainty, to fracture trust.

And if that fractured trust is not attended to, it may become shattered. The focus of attention is on the drama of the explosion, the drama of the medical catastrophe, but the shattered trust is overlooked. And that shattered trust is compounded and deepened if it's ignored. That applies to the trust that the workers have in their dedication to better care as well as the trust that patients and family survivors have had in the environment in which they seek care.

I came up with this couplet that seemed to say a great deal about the way I was learning about patient safety. Patient safety is a system experience, but patient harm is a patient experience, and if you want to know about harm, you've got to ask the patient. It seemed that patient harm was all about complexity. And there was nothing about my experience that was in the literature, even about complexity science, that reflected that patient harm.

When I thought about the patient safety analysis, I didn't understand the models of health care that they talked about. It seemed to me that this two-legged stool is a pretty good metaphor for what they described. There was the health care system as one leg and health professionals as another leg. And I thought, well, this is just not stable; this is not able to withstand the unexpected disruptions that you see in the definitions of systems resilience.

This model and other system models that I read about seem to be brittle by design. I wondered where's the patient? That the patient experience is the only way you can understand that full environment of safety, risk and hazard. So, bridging and cobbling in that patient experience to that two-legged stool to make a far more stable environment, seemed to be, it seemed to be logical. I thought that, well, the metaphor of the stool looks simple and that it is about complexity. But then actually, the three-legged stool is about independent strength; it's about support to others; it's about the complex force flows in that three-legged stool; and it really does provide for a greater capacity to stay upright if it's shaken.

So, to try to explain what that additional perspective from the patient side means is that here is this typical environment—we see so much safety literature situated in the hospital. Is it safe?

Well, let's see from a patient perspective to a layperson; this is a place of mystery. This is a place where the language is not mine; it's your language. You take away my identity when I arrive. I lose my clothes; I lose my name; I lose my relationships; I lose my homeland, my geographic situation, my relationships. My care plan may make no sense to me. So, safer is knowing what the plan is and having a navigator to help me sort it out all along the way.

At the time of illness, there's stress and new stress on top of all the other stresses we experience. There are the distressing symptoms; the disruption of all the other facets of life; the tipping points that are unrelated to health about managing how other people who rely on us are going to be OK while we're distracted by our illness and by our treatment.

And we know in COVID times, it really well illustrates the interconnected stress that we're all expected to tolerate. So, joining up and feeling like you're a partner in care relieves stress, if not actually resolving the challenges. So, I would say ‘safer’ is knowing I belong, I'm accompanied. Everyone needs to be at the table. We need clear communications, and that includes those in the patient's network of support.

I love the concept of whānau. It seems to me this is a really core idea of the connections being integrated into care. So, ‘safer’ is having a common language and continuous ways to maintain understanding. So very often in health care, for patients, there's always something new, and things are changing faster than we wish. It's hard to tolerate the confusion alone. And it's vital to have that translator and that guide.

So, ‘safer’ means increasingly, is having increasing help to cope with change, especially as things become less certain. ‘Safer’ is keeping up conversations to learn about risk, about anticipating and how to respond to risk, how to recognise those stressful situations the next time and know how to react. It's so important to learn about what's ahead, to have expectations filled in so that they're better aligned.

I think one of the most terrible aspects of health care failure is when our expectations are failed. And that oftentimes is quite avoidable if we make it clear at the start what the health professionals anticipate and what other patients who have had similar experiences can offer for what to expect.

When we follow an episode of care, it's so important to be able to recognise the waypoints as familiar. There's a huge, underused potential for partnering with peers to learn knowledge that's best or possibly only held by patients who have gone before on this road. So, ‘safer’ means connecting up with local knowledge.

Who's the patient? Well, to me it's inseparable from the family group, the whānau, the family, the next of kin, my people. It may take many forms. It may be the community group; it may be my neighbours; it may include the household pet.

This, I think, is actually the smallest irreducible unit in care. What happens to the member of the group affects everyone in the group, so all must play some part in the networks of trust; in communications, in planning and in planning care.

So, ‘safer’ is identifying and including the networks of trust and connection that we already have; ‘safer care’ is building more connections and ‘safer’ is care that demonstrates belonging.

So, how do we do this? What do we ask? How do we learn from each other? This is where it happens. It's one to one; it's open, inviting. ‘Safer’ is where trust is growing.

I used this slide back in November, and I think it captures a great deal. It's derived from some work I did with two junior doctors in the United Kingdom. And we were looking at how to provide medical students, who are very junior, their first experiences in a clinical environment.

What can they do to learn about their patients' interests? And one thing we identified was a question that was open ended that would not be onerous for the patient to answer. And it's a question that can be asked at any point in care. What can I do to improve your care today? This was the way the first question was framed. And it really gets at what are the patient needs? And it's very often that that junior caregiver can assist the patient in that moment. They can solve the immediate problem: I can't reach the water flask; I need to get to the bathroom. Or it can be more complicated, when can I see my doctor next? And then the student can go find the answer. So, it is about problem-solving as well.

The next question we developed was, what's the best you think you can be? And an open question like this – an open question being a question that does not have a yes or no answer but, instead, the beginning of a conversation. What's the best you can be? can help identify the patient goals.

What's one thing you wish you'd known? Well, this is a wonderful way to identify gaps in care, and very oftentimes, those gaps are issues that can be addressed immediately.

What's one thing that made a difference? Now, I love this question because it doesn't seem, on the surface, to be very useful, but the way we use that phrase in English implies something positive.

What's one thing that made a positive difference in your care? And, very oftentimes, we don't ask our patients about what we do well. So, here's a case where, yes, we can find out what assets we have in our system to offer our patients but also the assets that our patients bring to care as well.

What's one thing that made a difference? Well, it really made a difference when you explained my discharge instructions twice because the first time you did, I didn't understand, but when my partner was in the room, I did understand much better, and I also had the help from my partner hearing it as well.

So, the what’s one thing, the next one is what's one thing I should know about you? It's a wonderful open-ended question to begin a conversation about what matters. There's a phrase I've learned in the work that I've done over this last decade: ‘the small things are the big things’. And even being listened to can be a transformative experience.

So, the idea of asking these ‘what's one thing’ questions are to build capacity for both the question asker and the answerer.

And I would invite you to think about other questions that you can develop that begin ‘what's one thing’.

Now, why do I like those words? Well, if you ask someone ‘What should I know about you?’ or ‘What made a difference?’ or ‘What do you wish you'd known?’, it implies what's the most important thing you wish you'd known? What's the most important thing that made a difference? And that can be very onerous. It can be hard to decide and actually repress the confidence of the patient to answer it. So, instead of that, asking ‘What's one thing?’ kind of relieves the pressure. It's easier to come up with just one thing.

But, of course, it provides an opportunity for the question asker to listen closely and to hear what is ‘accepting accountability’ all about because, as you hear that answer, that conversation, as you listen to the patient, you, in fact, begin to own accountability for responding for that information.

And as you accept that accountability, you become vulnerable as well. I think that it's a core concept in building trust that, as we expose our own vulnerability and we build trust with the person we're with, it builds a bond. As that person speaks to you, they reveal their vulnerability, and that builds trust for them as well and you. And I think it's that foundation of humility and modesty that really underlies health care.

So, when do you do this? Well, you can do this anywhere. These kinds of conversations can happen in many settings – and I would suggest in any setting. And it is those conversations that underlie the medical information that's passed, the conversations that build the bonds, that the medical care depends on.

When Andy and Nick and I were working on this project, we took time to analyse what's called a force field. The force field analysis that's on this chart; on the left-hand side are factors and ways of looking at motivations and rewards for the actors that are supportive – What motivates us to act? What supports our courage to speak up, to act?

And on the right-hand side are restraining forces –What keeps us back? What keeps us from interacting with each other? So, I'll just take a minute to read some of these through with you.

For the driving forces, you can see how asking for a patient and family member to ask a question really validates who they are. Who I am matters. As I answer the question that I've been asked, someone's listening to me. It builds self-confidence. What I say matters. The legitimacy, my needs matter. And it fosters agency, so next time, it may be easier for me to speak up because I already have a conversational relationship. So, it fosters agency. It allows for gratitude. And, I think, in our health care system, broadly, we don't allow enough opportunity for patients to say thank you. And it does allow for this exchange of gratitude that I think is so vital for clinician’s life as well.

Now, for clinicians to listen carefully to patients and to ask these questions and to feel those support in those exchanges of information, it builds courage: I can ask you; I can step into this place of perhaps discomfort, anticipated discomfort. It develops core skills like that close listening. It also emphasises the person-centeredness of care: I can help you; I can act on some of these gaps, for example. It awards agency for the clinicians who may feel that it's such a complicated system, and they have such a little contribution; they can, they can improve care very specifically for this patient at this time. And, of course, it supports quality and safety work because they can recognise poor care after these conversations. In a light that’s meaningful for patients.

As for the restraining forces, you can see how those things that keep patients and family members from having this kind of conversation are such things as lack of confidence: Who should I talk to? I don't know who is willing to speak to me? The rapid interactions can be so confusing. I don't know what's happening in my care. I don't know what's next. I don't know what just happened.

There's also the traditional self-censorship: doctors know best, and, of course, I don't want to be labelled as a problem patient or a problem family member.

Now, for clinicians, very oftentimes the clinician will feel, well, this is unfamiliar: I wasn't trained to do this or, of course, the pressure of time: I've got a packed shift; I don't have time to do this (Of course, it takes only moments to be able to develop these kinds of relationships); the hierarchy: I'm too junior to engage in conversations with the patient about their care or the disempowerment: it's not my job; that's not what I do.

So, if we think about how these strong connections that we build contribute to safer care, I think you can see that they are the sinews of resilience: the capacity to continue to succeed in spite of unanticipated disruptions.

And the photographs here are in my health care system, and I think that they convey the strong relationship between the clinicians and the patients in a variety of settings, but they also relate to the security of the relationships among health care workers.

As with every other aspect of life, there are a lot of facets of who we are that influence the richness of our relationships and the barriers to our relationships.

So, seeing these interactions through the lenses of these and many other facets is important for both patients and practitioners. Yes, we are enriched by these elements of diversity, but we have to use them in our interactions. We have to recognise them and respect them. It's always care for this patient within their unique network of relationships. And it's teams of these health care workers who hear and see with these sensitivities and insights. And this knowledge really does expand our appreciation of what good care is.

You know, we talk about CarePass, and we talk about this imagined model of person-centred care, but, as we say person-centred care, it is incredibly diverse and incredibly different for each person. And that is something to celebrate. This knowledge really brings about new forms of creativity and innovation. We just have to be open to it.

In my work over my lifetime and community organising, I learned this motto of strength and diversity – and I think that that really is what we are doing. We are doing a form of community organising. This picture is one of my favourites, depicting what health care is all about.

So, we can see the dark clouds up in the sky – that's risk. And we can see the brighter light at the horizon that we're heading for on these two tracks that seem to head off forever into the distance – and that's the reward that we share as the practitioner and the patient.

And then out over on the right-hand side is a little bit of a stormy area, that's kind of unknowable; it's hard to tell if that's a downpour or just sprinkles and if it's going to cross our path or not.

So, when we think about this environment in which health care takes place, we can pose the question, who leads the health care team? And the answer to me is obvious: the patient always leads, but we travel together. We identify with the risks; we identify together with the rewards and we identify together the unknowables. But we do travel in ways that are intertwined with each other, and we are affected by the experiences of the other.

This is what those networks look like. Building trust in the care team; building trust between patients and clinicians; building trust between families and the public. Frontloading trust, I think, can help everyone through the unexpected.

So, a question arises in my mind and yours, probably, of how do we motivate and sustain this commitment? There's some work that was done almost 15 years ago by Daniel Pink, an American writer, in a book called Drive. And what he tried to identify was those factors that distinguish between the job you love versus the job you hate. What are the elements of a job that really sustains your motivation and satisfaction in the work?

And the first factor that he identified is the urge to direct our own lives. And I think you can see this both for the health care worker and for the patient that that degree of autonomy and responsibility can be a sustaining factor in the commitment to each other and the commitment to better care. Mastery, the support to get better and better at something that matters.

So, supporting patients to learn more about their condition; learn more about how to provide themselves with better care and how to interact with other people who have similar experiences and knowledge to share.

This mastery, if it's supported, for clinicians and health care workers as well, can be a factor to be committed to the relationships that we've talked about.

And finally, purpose: the yearning to serve something bigger than ourselves. And I think this is – an example is your commitment. I think everybody in the audience today has this commitment to patient safety and to higher quality care. And to be able to be supported in that is really important.

Inviting our patients to be involved in issues that are bigger than themselves, that is, improvements in the system, helping other patients, I think is an opportunity that we need to develop.

But what I would say about autonomy, mastery and purpose is that, in health care, the context in which these are realised is relational. It really is in the partnerships.

Much of the work that I've done is focused on the next generation of clinicians, and that really is because I believe change happens generationally. We can do lots now by creating an inviting environment for students who become practitioners in an environment where dignity and respect are highly valued; where information sharing is a core skill; where participation and active responsibility to take a leading role, to become a leader and to collaborate; that these are the ways in which I think future health care workers are being trained, and we need to provide an environment that's encouraging for that and take full advantage of their energies.

Now, I said I would speak a little bit about some of the other roles that I take in health care system. And it really is based on many of the ideas I've just described, contributing to something larger than myself. I'll mention just a few of these.

In my introduction, you heard that I was awarded recognition as a patient safety champion for Canada back in, I think it was, 2016. And I used that as leverage to open other doors: I use that as a way to encourage others to pass on that recognition by mentorship and by collaboration with peers to encourage other people who have far more imaginative ideas, much better knowledge, different ways of presenting themselves to advance their work as partners in health care.

I've been a team member with health improvement teams; I am involved with quite a number of research projects now that are about the patient partner experience to better understand why do people volunteer and what are the rewards that they expect from successful partnerships in health care research and improvement projects in governance?

One of the pieces of work that I very much enjoy is writing interview questions for admission to the medical school in British Columbia. The University of British Columbia has the largest doctor training programme in the country, and it's such a privilege to be able to be involved as a member of the public, as a patient, in who are tomorrow's doctors, who are the people who will get a chance to train. And I love public speaking. And, as I said, it's been just a great privilege to be with you.

I'd like to leave you with a quote from my favourite Canadian sociologist, the way he's talked about health care. And Arthur W. Frank is his name, emeritus professor from the University of Calgary.

‘In clinic, at the bedside, where it counts, a health care system is people touching each other. Everyone who touches anyone affects that person's healing and affects the further demoralisation of medicine or its remoralisation. In the moral moment of that touch, there is no system.’

And I think I believe that statement so beautifully encapsulates there is no excuse to say, well, the system is that way. We all have an opportunity to make a difference one on one. So, with that, I'll thank you very much for your attention, and I invite you to correspond with me – here's my email address at the university.

I wish you the very best of luck in your work and a successful conference over the next few weeks. The subsequent presentations will be exciting, and I'll be following them as well. Thank you so much.

# 'Health reforms: Consumer and whānau voices' by Deon York, assistant director partners in care, Health Quality & Safety Commissio

OK, so, today we're going to talk a little bit about the health reform programme as it pertains to the consumer/whānau work. So, particularly focusing on the code of expectations and that idea of sort of turning the tap up.

So, first of all, I'm just going to cover a little bit about He Hoa Tiaki, the Partners in Care programme and the consumer voice work. And then we're going to look at the code of expectations.

So, what is the purpose of this code? How is it being developed? And what are the potential implications for you?

So, you’ll notice on the title slide, I talked about turning the tap up. Well, we believe that consumers, family, whānau and carers are the most untapped resource in the health system. And we've been saying that for some years, and we continue to believe it.

So, on one hand, we believe, yes, the tap is turned on and that now I think people increasingly recognise the value of involving consumers and whānau in the design and delivery of services. But, you know, there's a real opportunity as well to turn that tap up and really get it going.

So, a little bit about He Hoa Tiaki Partners in Care programme. So, it's been a strategic work programme of the Commission since September 2012. And the goal over time; it has evolved, but it has not changed. And that is really to foster and promote partnership and shared leadership. And that's between consumers and whānau and health and disability service providers or in maybe the new speak, ‘health providers’.

But, of course, that doesn't mean that health providers are not providing services for people with disabilities and that that's not a factor as well. Absolutely it is.

So, the aim, of course, has been founded on evidence that involving people and whānau in true partnership at all levels leads to overall improvements in the quality and safety of the system.

And what we're talking about when we're talking about all levels, we mean at the level of direct care, at the policy level and at the governance level. So, for it to be truly successful, it needs to be at all these levels.

So, there are three components of work that the Commission are working on in relation to the health review work programme. The first is a structure for a national consumer health forum, which could be the topic of a completely different talk, a centre of excellence for consumer/whānau engagement. Again, that could be a topic in itself.

But what we're going to focus on is a national set of expectations for how all health entities engage consumers and whānau. This slide is really just to show the timeline for this work and to see how it fits in with the other pieces of work.

So, if you have a look on your screen there, you'll see that we're in the period now of October to May really where we're developing a range of partnerships with the interim entities; we're thinking about the series of forums or fora that we are producing; we're expanding the centre of excellence function and we're in the consultation or towards the end of the consultation phase on the code of expectations. And, of course, the legislation will be passed towards the end of the government financial year. And then from July 1st, the new ceilings will be in place. Of course, that doesn't mean that everything magically changes on July 1st, but certainly the structure starts from that time.

So, OK, the code of expectations for consumer/whānau engagement; it's important to note it will apply to health entities. And what do we mean by health entities? We mean entities, such as Health New Zealand and the Māori Health Authority. But also, interestingly, although we're developing the code, we also will abide by the code as the Health Quality & Safety Commission. Of course, there are implications for care as well and services that are commissioned from health entities to those services when it comes to the code.

So, the developmental draft, it's principles-based. It was deliberately done that way for widespread consultation. And, as we receive the feedback, it will focus more on some of the practical application of the code so people can really see themselves in it – that's both the clinical community and the consumer community as such.

So, the actions centre on involving consumer and whānau at all levels. I think it's important to note that the developmental draft was not developed in isolation; it was developed with a team. And that includes Te Kāhui Mahi Ngātahi our consumer advisory group. This is just to show you who is currently on that group. And also that we've expanded recently that group in recognition of the expanding role of the commission and consumer/whānau engagement.

We also had a lot of input from Kōtuinga Kiritahi, which is our consumer network, which currently has 11 members, and we also have recently five newly appointed members. And what they looked at really was from the consumer/whānau perspective – could they see in this developmental draft themselves and what we were putting forward to the wider community?

And, of course, that's always really interesting debate around everybody seeing themselves in a document and how we make sure we do that.

So, the principles of the code are very much underpinned by Te Tiriti o Waitangi and WAI 2575. And we've had some very positive feedback about that. And, I suppose, on the values front, there are four key areas.

One is around relationships of mutual respect and inclusiveness.

The second is equity.

Thirdly, it's about valuing consumer/whānau contribution.

And finally, an underpinning, of course, commitment to quality, safety and, crucially, cultural safety.

So, you can see from these statements very much a principles-based approach to the draft which is in development. And each of these, there is an explanation for each of these in the code documentation itself.

Something else to note, and probably particularly of interest for those of you watching this, is the second point on this slide that health entities must act in accordance with the Code of Consumer Participation.

At the moment, in the Pae Ora Bill, it is referred to as a ‘code of participation’. And there are various discussions and debates over what the final wording will be. But, whatever the final wording is, this is

talking about the code of engagement that we are developing. Also above, you also see there an expanded role for the Health Quality & Safety Commission. I guess the Commission has been fulfilling this role for some time. And, in a way, this is just formalising that role.

But it does lead to some questions when you see that health entities must act in accordance with this code. What does that really mean?

So, what we've been hearing, overall, is that there is support for this code and its intent. And it's about reinforcing and connecting voices, not replacing existing networks and communities or indeed codes. A very important point in the consultation process so far is that we want to complement existing legislation and not confuse. So particularly around the Code of Health and Disability Services Consumers’ Rights, which is administered by the Office of the Health and Disability Commissioner. That pertains to direct care. And, of course, there's a well-established process for that.

So, anything that we put out there, we want to make sure that it's not in any way confusing the public on that front. Feedback we've been hearing is people need to see themselves in this work that we've been doing. There needs to be multiple avenues for feedback. There can be an emphasis on the importance of co-design (it's already in the document, but it needs to be emphasised). And also just underscoring the importance of Te Tiriti o Waitangi in this code development.

So, thinking about you, what does this code potentially mean for you? Well, some of those questions we can answer. And some of them, we're still working through ourselves.

So socialising consumer and whānau engagement in your organisation, which happens in many places already, will just become even more important; and I guess this idea of involvement at all levels, when we talk about the direct care, the policy and the governance level, is actually showing that that's happening in a meaningful way; seeing consumer engagement in action when services are commissioned; and also thinking about how this can be sustained in your organisation. So, whether that's as a result of services being commissioned or whether that's a result of local initiatives, it applies, the code applies in both of those cases.

So, I guess the more thorny questions that we're giving consideration to right now are what teeth will this code have? You noted in the previous slide it talks about people acting in accordance with this code. So, we want to understand better what that means and how it will integrate with the other frameworks that are in development. And we will provide advice on that.

Secondly, how might it apply system-wide, service-wide or in terms of one-to-one relationships? That's an important consideration as well.

And I think finally, how will we know we have succeeded? So, putting a code in place in and of itself doesn't necessarily change behaviour. So, how will we know? And how can we measure that we've succeeded? I'm just putting up one example here.

There are many ways that we're thinking about how this can be measured. So, I just want to emphasise this is one metric for doing so. But thinking about the consumer engagement quality and safety marker, currently all 20 DHBs have participated in this. And what this is is a self-assessment of how DHBs think that they're going overall when it comes to engagement on a scale of one to four with definitions of what each of those phases is and with examples uploaded.

Now, importantly, this is not just the service deciding what number the service will give itself. It's also done in collaboration with the community. When it's done well, that's how it's done. And so, this is not really—as with a lot of the data that the Commission collects—it's not for judgement, it certainly is for quality improvement. So, in some ways, the number itself is less important. What's more important is that there is a discussion taking place about consumer engagement activities and how they might, or might not, have an impact on the quality and safety of services.

So, you can see here on this slide, as well, just an example where Counties Manukau have shown what they've scored for engagement, responsiveness and experience. And we would consider this a very good submission. And they've also given the examples there, the quick narrative of what the examples are—and if you were to click to the right, you would be able to see the full example. And above, you can see where they score in relation to the other DHBs.

I think a note of caution on this is this is also linked to the adult and patient experience survey and the primary care survey. And we know that representativeness by ethnicity for Māori and Pacific, and in some of the previous runs for Asian, has been lower. And so, therefore, we can't solely rely on these types of data as well, which was to my point about this being one metric and one example, but this is a starting point for us to think about how we measure the code and how we measure its effectiveness.

So, thank you very much for listening to this one aspect of the consumer voice work being undertaken by the Health Quality & Safety Commission.

And if you have any questions, always feel free to get in touch.

Thank you.