**Leaning in to lessen fear: How structure can free clinicians, patients and their whānau in exploring what matters most**

**Accessible transcript**

Audio

All right, hi, everyone, and thank you for having us and for attending this session. It's called Leaning in to Lessen Fear: How structure can free clinicians, patients and their whānau in exploring what matters most.

**Visual**

**An image of two women standing close together, smiling at the camera, fills the top half of the screen. Overlaid text on the image reads ‘Ō tātou hiranga | What matters to us, Shared decision-making and advance care planning virtual hui, 2–3 December 2020. The bottom half of the screen is white and there is black text on the left-hand side which reads ‘Leaning in to lessen fear: How structure can free clinicians, patients and their whānau in exploring what matters most’. There are three names listed on the right hand side: Jo Paladino MD, Joshua Lakin MD and Rachelle Bernacki MD. In the top right corner is a logo which reads ‘our voice tō tātou reo, advance care planning’. Joshua Lakin is shown in a box to the right-hand side. Joshua has short clipped brown hair, a short brown beard and is wearing glasses and a blue shirt. Beneath him in a separate box is Rachelle Bernacki. Rachel has a short blonde bob and is wearing glasses and a purple blouse. She is sitting a room with a desk and table visible behind her.**

Audio

So, first, before we jump into our presentation, just wanted to stop for a couple of acknowledgements. So, first…

**Visual**

**A white PowerPoint slide appears on screen. 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’. Down the left-hand side of the screen runs a light green kowhaiwhai pattern. This layout appears on all of the following slides. Josh and Rachelle are pictured alongside the slides.**

Audio

Kia ora tātou. Ko Mt Hood te maunga, ko Williamette River te awa, nō Oregon ahau, ko Laking tōku whānau, ko Josh tōku ingoa.

**Visual**

**The next slide appears with Joshua’s mihi shown; he reads this out loud. Alongside the words are three images of different outdoor settings: a snow-capped mountain with a lake in front, a tree-lined river and a forest with ferns and sun shining between the trees.**

Audio

Kia ora tātou. Ko cedilla te maunga, ko Charles River te awa, nō Brooklyn, New York, USA ahau. Ko Paladino tōku whānau, ko Joanna tōku ingoa.

**Visual**

**The next slide appears with Jo Paladino’s mihi shown; she reads this out loud. Jo appears in the video box alongside the slide beneath Joshua, she has long brown hair and wears a black cardigan and glasses. Alongside Jo’s mihi are three images of different outdoor settings: a canyon with the sun setting above the ridge line, a city scape of tall buildings surrounded by trees and a lake in front, and a city view between two buildings looking up at the Brooklyn Bridge in New York City.**

Audio

Kia ora tātou, ko Kissing Bridge te maunga, ko Lake Erie te awa, nō Buffalo NY ahau, ko Bernacki tōku whānau, ko Rachelle tōku ingoa.

**Visual**

**The next slide appears with Rachelle Bernacki’s mihi shown; she reads this out loud. Alongside the words are four images of different outdoor settings: a snowy ski slope lined by trees with a chair lift running up the middle of the hill, a light house on the shore of a lake, a cityscape lit up at night and the Niagara Falls with a small ship in front.**

Audio

So, we're delighted to be here today to describe the principles behind the Serious Illness Care Programme, which is really a structured, systematic approach to ensuring that patients and families have opportunities to talk with their clinicians about what matters most and really to drive more, better and earlier conversations. We really designed the programme to make it easy for clinicians to do the right thing, to have these conversations and to really take away the system barriers that make it difficult to initiate these conversations. However, in the last seven months since facing the COVID-19 pandemic, it's been really challenging to have these conversations. We've noticed this ourselves as clinicians, in that there's tensions in bringing this up, and we ourselves feel anxious, as well as our patients are experiencing a high degree of anxiety along with their families. So today we'll talk through some of that and think about ways to mitigate that anxiety, both on behalf of us to make us feel more comfortable, but also for those that we serve. And we will talk about the tested language that we've used in these conversations that are iterative. It's really important to make sure that these conversations can happen repeatedly. We'll also spend a little bit of time talking about the challenges of doing these in in-the-minute virtual settings, like we are right now on Zoom, or even over the phone. So, with that, I'm delighted to turn this over to Josh, who will take us into the principles behind the Serious Illness Care Program.

**Visual**

**The next slide appears. Joshua disappears from the screen and Rachelle is pictured alongside in a small box. On the slide is a list of bullet points which she outlines as she speaks.**

Audio

Thank you, Rachelle. (CLEARS THROAT) So, I'm going to start today by giving a little bit of background and kind of talking through this programme and where it came from and why we think it can be helpful, or aspects of it can be helpful, for conversations that really drive anxiety. And so, first, just to take a step back and talk about what it is that we are talking about, we're focusing here today on talking about early conversations about what matters most to patients — their goals, their values, the things that they do that makes them feel like themselves, things that make up a good day. Talking about those things for patients in the context of a serious illness and in the health care setting, we have evidence that that makes care better. And the evidence is a little complex. It's in specialty palliative care literature. It comes from advanced care planning, information and studies and then also from serious illness communication and shared decision-making models. And what we've seen in those different studies is that talking to people about what matters to them helps to line up the care and the things that we do in the health care system with what matters most to them. So as best as we can measure it, and it's tough to measure, we are able to better serve the people that we are providing care for. We also see that we improve, or these conversations help to improve, quality of life and patient well-being. In the United States, at least, we see more in earlier hospice care, which feeds back into some of those better patient outcomes and also fewer hospitalisations, which is a place where end-of-life care is associated with more— Being in the hospital at the end of life is associated with more traumatic end-of-life experiences. And then probably most important for me as a palliative care clinician is... these conversations improve the experience of serious illness. They allow for better patient and family coping and bereavement outcomes, making living in... living the best you can in this difficult time easier, which is very important.

**Visual**

**The next slide appears. Rachelle's video preview disappears and she is replaced by Joshua. On the slide is a heading which reads 'Early conversations about patient values makes care better.' Beneath the heading is an image of a female doctor with black hair tied into a ponytail. She is wearing a white lab coat, has a stethoscope draped around her neck, and is holding a piece of paper. She is looking at the patient and has her hand placed over top of the patient's hand. The patient has her back to the camera. She is wearing a beige jacket and has short, white hair.**

Audio

However, if we do this, or if you believe that we... that these are good and helpful for patients, for whānau, for clinicians, we don't lean in, and we don't lean in for a lot of different reasons, right, and we'll talk a little bit more about that. But we've known, and we've seen evidence that these conversations, they don't happen for many patients that need them. If they do, they tend to happen late in the last days to weeks of someone's life when there's not much time for us all to do our work. They tend to focus on what matters to us in the health care system. We ask people about do they want CPR and feeding tubes and medical things. We don't ask them about the things that matter to them in the way that they live their life. And then last, in the context of very complicated medical records and electronic medical records, they're hard to find. So if that happened, it's hard to get the information back out of the system. And the reasons for this are... many, right? So, we've trained a lot of professionals and worked with a lot of different kinds of professions over the years doing this, and none of us are really well trained in how to do conversations like that. We each bring different skills, but we don't have great training as clinicians. Especially in the United States, there is fragmentation of care, multiple specialties, multiple settings, and we ask patients to dance our steps rather than try and make it easy for them to come to us. There are variations in attitudes, in beliefs, in practice norms in serious illness communication, And they vary from specialty to specialty and place to place, which makes this challenging. There is an increasing notable attention to clinician burnout and moral distress across all different professions of clinicians. These are difficult conversations, right? Emotions run high. There's reluctance on the side of both of us — patients, families and clinicians — and there's also worries about harming each other. We worry about hurting our patients, talking to them about hard things, and our patients worry about us too — about disappointing us or making us sad. There's diverse cultural considerations around serious illness and death, and those vary immensely from place to place. There's prognostic uncertainty about thinking about the future and planning for it. So what this all leads to is increased anxiety, right, amongst other things, but definitely increased anxiety amongst — as Rachelle pointed out — clinicians, whānau, patients. We all feel anxious in this space, so we lean back rather than leaning in to have these conversations.

**Visual**

**The next slide appears. A stick figure of a person is shown leaning against a wall. There is a title alongside which reads 'Yet we don't lean in.'**

Audio

And on top of that, as Rachelle mentioned, these are extraordinary times, and we're facing unprecedented challenges. So while we might argue that patients and clinicians and health systems and countries face, kind of, a burning platform to talk a little bit more about what matters to patients in the context of this pandemic, we are also seeing... that doing so involves negotiating some pretty complex and evolving situations, right? So patient care has changed. Patients are often in the room by themselves without family or visitors, or we're doing it like this. We're doing things over Zoom platforms or by telephone. Clinicians are working more and harder in a lot of places and often fearing for their own safety in the context of this virus. And, at least in the United States, we have seen solid data that this virus and the way that the health care system in our country responds to it are worsening pre-existing systemic inequities and disparities. And so there's a lot of things that come together to make these times tougher, and what that does is it increases the anxiety further, right? So these are very anxiety-laden conversations right now. And yet, as I pointed out at the beginning of this slide, it's also really important to have them right now.

**Visual**

**The next slide appears. The heading reads 'This is an extraordinary time with unprecedented challenges'. Beneath the heading are three images. The first is a person wearing blue jeans, a black jacket and a white face mask walking down an empty street. The second is a hospital intensive care unit with approximately six beds lined up. There is a patient in each bed and a health care professional beside each bed, wearing a full protective suit.**

Audio

So what I'm going to do next is talk a little bit about an argument that a framework and structure can help in times of anxiety. And so there are a number of different ways to kind of frame and structure these conversations. There's many good ones. We are— We have worked the most in the context of the Serious Illness Care Program, and so we'll use the Serious Illness Conversation Guide as an example of structure to think about how to use structure and lean on structure to ease anxiety. And what the guide is really a framework of best practices to help navigate a tough situation. And it feels kind of weird to me. As a palliative care doctor, I was taught to follow the patients in these conversations, that conversations about goals and values, goals of care, it's an art form, which it is in many ways, and at the same time, a structure is helpful in times of anxiety. This guide just kind of comes out of the construct of checklists, right? And it's kind of a weird thing to think of a checklist for a conversation like this. At the same time, if you think of the other applications of checklists, they are built for adding step— or creating structure and steps to help people, humans, get through complex emotional... processes, right? So kind of the best example is landing a plane. Right, so imagine good pilots — when people started to talk about putting a checklist together for landing a plane, they would say, 'But landing a plane is a complex art form 'where people... you need us good pilots to do it.' And that is true and remains true. However, I think we've seen that taking that very complicated set of actions that it takes to land a flying, extremely heavy piece of large metal with a bunch of people in it and putting it into steps helped increase the safety and consistency of landing a plane. And it's not that this guide is a checklist, but the idea of structure, of following steps in times of anxiety when there's humans involved, is where the idea comes from.

**Visual**

**The next slide changes to show a preview of the serious illness conversation guide form. On the left hand side of the form is a lilac coloured box which runs from the top to the bottom of the screen. Inside is a title in white text which reads 'A framework for best communication practices'.**

Audio

So, let me talk a little bit about those key steps — the scaffolding and structure that this guide is on. So, first, is setting up the conversation, so starting by laying the groundwork about what we are doing today to create space to do something different. Lead patients gently into a conversation — and ourselves, and get ourselves prepared to go through the conversation. The next step is working to assess a patient's information needs and family information needs, so whether they understand, or what have we already taught them as their clinicians about what's happening with their health or their body, and then learning from them what they need from us. So how much information do you want from us as we go through this conversation? So learning where they are and how we can help is the next step. Then it's delivering a prognosis, or delivering information about what the future will hold. So many— At least in the doctor world, people tend to think of delivering a prognosis as predicting how many hours or days someone will live with a constellation of illnesses. But that's not what it's about for these conversations. For these conversations, it's about pinning a view of the future in the very realistic uncertainty that we face so that we can make some shared decisions and thinking about how to best care for you as we go forward. The next step is to explore what matters most to the patients. Ask them about their goals, their values, their fears and worries. Explore the kinds of things that they know about themselves that we can use as we think about their health and their health care. And then last is pulling that all together, summarising what we've heard, making sure that we heard them correctly, and then making a recommendation based on their goals for how to proceed forward.

**Visual**

**The next slide appears. The purple box disappears and is replaced by a heading in black text which reads 'Key steps'. As Joshua speaks, text boxes appear down the left and right-hand sides of the screen. The boxes are light blue with white text and read 'Set up the conversation', 'Assess patient information needs', 'Deliver a prognosis', 'Explore what matters most' and 'Summarise and recommend'.**

Audio

And the guide is the scaffolding. Now, those are the steps, but there's lots of things you need to do to be able to move between those steps. So I wanted to highlight some of the key skills that help us climb and navigate and slide through that scaffold. So, like we mentioned, it's an emotion-laden conversation, so having some skills and responding to emotion is really important as you navigate this guide, tending to the emotion in the room — the patient, family and our own. Asking clarifying questions, so in the context of cultural diversity, of... anxiety, of around expressing what matters most to us, going deeper and asking some questions to get a better understanding about people's answers to these questions is an important skill on top of the scaffold. Next is asking permission, a critical skill in the context of anxiety; handing power and control over to patients and whānau in times when it's not a time when they feel in control. And also checks, right, to make sure that they're ready to go forward, not bulldozing ahead without their... without them following along. And then employing bookmark statements, so capturing those things that come up that are really important that you need to come back to, such as, 'I hear that you're afraid of having a lot of pain. 'I have some thoughts about that, but let me ask a few more questions. 'Then we'll really dig into the pain that you're afraid about.' And we'll work on that, but I'm going to come back. And then last, listening carefully, reflecting back, making sure you're hearing them and also making sure that you're capturing and engaging them in the conversation.

**Visual**

**The next slide appears. The heading is replaced with a new one which reads 'Key skills'. As Joshua speaks, text boxes appear down the left and right-hand sides of the screen. The boxes are light blue with white text and read 'Asking permission', 'Responding to emotion', 'Employing bookmark statements', 'Ask clarifying questions' and 'Listening actively with reflection'.**

Audio

So, then, last, just to point out — so as part of, kind of, thinking about this guide and bringing it to New Zealand, the New Zealand Government a few years ago took some time to think about adapting this to the setting in New Zealand. And they had three co-design workers, who are consumers and clinicians, and after getting input in locally, there's thinking that they'd do a few key changes that I just wanted to point out. So the first, critical to the cultural work around medical decision-making in New Zealand, is checking to make sure that we have the appropriate whānau in the meeting and that they are participating. So there's a dedicated step to that. As they went through the focus groups, they found that the word 'worried' didn't work in this context, and so they've replaced that with the word 'concern'. And then, last, in the context of New Zealand, which tends to be less religious, there was some feedback on the strengths question from the American version of the guide, and that question was replaced with, 'What helps you through the tough times?' It's a wonderful example of getting collective, broad input into the structure that we had started with and adapting it locally, so I encourage you all to take a look at that. And with that, I'm going to pass it over to Jo, who's going to walk through some more of the data and the impact of the programme and the guide.

**Visual**

**The next slide appears. The heading reads 'Adaptations to the SICG - Aotearoa 2018'. There is a visual of the Serious Illness Conversation Guide Aotearoa. Three arrows appear down the right-hand side, pointing toward the image. Text next to each arrow reads 'Checking on whānau participation', 'Prognosis: Replacing the word "worried" with "concerned"' and 'What helps you through the tough times?'.**

Audio

As Josh mentioned, there are many systemic forces and obstacles that get in the way of having high-quality, meaningful conversations about what matters with patients and those they love. And so as a programme, we designed the Serious Illness Care Program to see if we could close some of the gaps that we see based on this idea that health systems need a process and a systems approach to support these conversations to happen with high quality and routinely as part of care. And so the Serious Illness Care Program includes clinical communication tools, like the Serious Illness Conversation Guide that we just saw. The guide is also paired with supportive materials for patients and their families, as well as clinician training programmes and system supports, such as locally driven workflows to integrate conversations into very busy clinical practices and electronic health record templates to document conversations in an accessible location in the medical records so they can be found. So I'm going to share what we're learning from our research efforts about the experience and impact of having these conversations using a structured approach.

**Visual**

**Joshua disappears and is replaced by a video of Jo. Alongside Jo is a slide with a heading which reads 'Serious illness care program' and three bullets are listed below. On the slide is a list of bullet points which she outlines as she speaks.**

Audio

We tested this intervention with tools, training and systems changes in a randomised clinical trial in oncology, with 91 oncology clinicians and 278 patients with advanced cancer. Nearly 60 percent of the patients died during the trial. We found that this intervention led to more, earlier and better conversations about what matters to patients.

**Visual**

**The next slide appears. The heading reads 'Randomised trial of the serious illness care program in oncology'. There are two bullets listed which Jo talks through.**

Audio

So to give you an example, nearly 90 percent of patients in the intervention group who died had a documented discussion with their clinician about their personal values and goals, compared to fewer than half of patients in the control group. Conversations also happened significantly earlier in the illness course, about five months before death, compared to two and a half months. And this gives patients and their families more time to plan and prepare for the future with their illness.

**Visual**

**The next slide appears. The heading reads 'More, earlier, better conversations' and there are two bullets listed beneath. Jo talks through the information bullets as she speaks.**

Audio

We also found that the intervention resulted in less... significantly less emotional suffering for patients, including half the rates of moderate to severe anxiety and depression symptoms for patients in the intervention group compared to the control group. And lower rates of anxiety persisted for months after the conversation.

**Visual**

**The next slide appears with a heading that reads 'Patients experienced significantly less anxiety and depression'. There is a chart which shows the amount of anxiety experienced by patients in the control group and the group that had the intervention.**

Audio

We didn't see an effect on goal-concordant care or peacefulness at the end of life or on resource use or health care utilisation at the end of life. We had a lot of trouble implementing those measures, and this really highlights the need for better measures that capture the experience of care and the impact of these conversations over the trajectory of care and not just at the end of life.

**Visual**

**The next slide appears. The heading reads 'GCC and PEACE were null' and there are two bullets listed beneath. Jo talks through the information bullets as she speaks.**

Audio

We also wanted to learn and understand from patients and clinicians about their experience with these conversations using a structured guide. And so what we found when we studied this is in the oncology trial, there was high uptake of the Serious Illness Conversation Guide, with 87 percent of clinicians using the guide and 90 percent reporting that the guide was effective and helpful in helping them understand patients' values and priorities. And the average time of the conversation was 14 minutes. So they can be— You can build this conversation into a routine visit during your practice. And 80 percent of patients found this conversation to be worthwhile.

**Visual**

**The next slide had a heading which reads 'Serious Illness Conversation Guide: High feasibility and acceptability'. On the slide are statistics about the guide which Jo talks through.**

Audio

And in their own voices, patients describe the impact of these discussions on their lives. For example, some patients shared that the conversation helped them plan their medical care, such as, 'Making a list of my last wishes, 'such as when I can no longer go to the bathroom by myself, 'I would like hospice.' Other patients talked about enhanced communication with their family members. For example, this patient mentioned talking to their two grown children about how they're doing. 'I don't want to keep them in the dark, so nothing will be a shock.' Patients also reported a focus on planning practical activities, surfacing of their goals and their priorities, as well as a direct improvement in their own well-being, such as feeling less anxious about the future. Patients also shared that this conversation helped them feel more connected and closer to their clinician.

**Visual**

**The next slide appears and the heading reads 'Patients describe positive experiences'. There is a list of bullet points which Jo talks through.**

Audio

And when having these conversations, in summary, we learnt that we were seeing the impact on patients' lives and not just on their medical treatments, and that when asking patients open-ended questions about what matters, patients felt more prepared to face subsequent health challenges, more connected to their clinicians and loved ones, and also more empowered to set and achieve goals without added distress and actually with better psychological outcomes. And so moving on to primary care work, we were really thinking a lot about how this programme could be adapted to the primary care context. And we conducted an implementation research trial that was led by Josh and Rachelle and colleagues in primary care at our home institution, testing this intervention, tools, training and systems changes in primary care with inter-professional clinicians who care for patients as part of a care management programme. So this included nurse care managers, social workers, advanced practice clinicians and physicians, primary care physicians. As you can see, many of the patients in this who were part of this trial had multiple illnesses, and many were older adults.

**Visual**

**The next slide appears. The heading reads 'Primary care trial: Patients were predominantly older adults with multiple illnesses'. Beneath the heading is a table which outlines the baseline characteristics of deceased patients in clinics that implemented the serious illness care program an in comparison clinics.**

Audio

We found that this programme led to more... more accessible and more comprehensive conversations, which were documented in a more accessible location, which is important because it makes the information actionable to other clinicians who care for the patients.

**Visual**

**The next slide appears. The heading reads 'More, better and more accessible conversations' and beneath the heading are four charts which Jo talks through.**

Audio

And one of the biggest learnings from our work in primary care, we really focused on expanding how we think about prognostic communication. So as clinicians, sharing prognosis is one of the hardest things that we do. It's difficult for clinicians; it's also really difficult for patients and loved ones to hear difficult news about what may be ahead with an illness. And most people think of prognosis as focusing on life expectancy. Not only is time increasingly difficult to predict, but it's not always the most helpful information for patients and families. Some patients may not want to know about time. For others, they may want to know information about the future, but they may want their families to have this information or to have this information together with their families. And so we really learn from our primary care colleagues that helpful prognostic information relates also to anticipated functional changes, as well as preparing for unpredictable, sudden changes in the future. And so on the guide, we expanded the prognostic framework to include time, function and unpredictability.

**Visual**

**The next slide appears and has a heading which reads 'Sharing prognosis requires a more expansive framework'. Beneath this are three words in blue text 'Time', 'Function' and 'Unpredictability'.**

Audio

And this is really supported by research. This is research from colleagues out in San Francisco. This is a study in older adults that showed that 75 percent of diverse older adults want to know their prognosis. And the reasons they want to know about the future are not just about the medical details. So the most common reason is to prepare for the future. Patients also wanted to have information to make the most of life and to make medical- and health-related decisions.

**Visual**

**The next slide appears and has a heading which reads 'Many older adults want to know their prognosis even in the face of uncertainty'. Beneath the heading is three bullet points which Jo talks through.**

Audio

And so here is an example of a prognosis that really focuses on function. “I **hope** that you can maintain as much independence as possible and we will work toward that goal. I’m also **worried** that you may get weaker over time and may not be able to live on your own as your disease progresses.” With a pause to allow silence for the patient and/or their family to process. In this instance, this is a patient who may have years to live, and discussing a functional prognosis can help the patient, family and clinician make plans to maximise the patient's independence, especially if that's a primary goal and priority for the patient, to maximise the patient's independence as much as possible and also prepare for future changes.

**Visual**

**The next slide appears and has a quote centred across the middle. She reads this aloud.**

Audio

How can we give patients meaningful information in the face of unpredictability? Here's an example of this kind of prognosis. “It can be difficult to predict what will happen with your illness. I **hope** you continue to live well for a long time and we will keep working toward that goal. I’m also worried that you could get very sick suddenly, and I think it is important for us to **prepare** for that possibility.” Pausing and allowing for silence again. So what's consistent here is the hope-worry or hope-concern model and hope-prepare language. And one of the primary roles of these conversations is to really provide emotional support using compassionate language, pausing, taking a breath after sharing news to give time for the patient and their family to process. And this creates space to respond to their emotions. And so one of the takeaways from this – to address the anxiety that comes with thinking about the future with an illness and planning for the future, prognosis has to be personal and really has to be tailored to the patient's and their family's unique communication needs. And so even before sharing prognosis, asking what kind of information would be helpful and how patients want to receive that information can really help clinicians tailor the prognostic information to the patient's needs.

**Visual**

**The next slide appears and has a quote centred across the middle. She reads this aloud.**

Audio

And in addition to different illnesses, people have enormous diversity of cultural backgrounds and social contexts that inform their experience. And so we're at a moment with a pandemic during a time of significant social change in which new light is being shed on long-standing and deep-seated systemic inequities and systemic racism and the disproportionate negative effects on the health and well-being of communities and people of colour. And so partnering with communities as well as health systems that serve people who are under-represented and marginalised by our system is a focus of our programme and many others in health care. And so early work... Some of this early work for our programme involved conducting focus groups in partnership with colleagues in South Carolina. And these focus groups took place with African-American patients with advanced cancer and their caregivers, as well as members of a church group in South Carolina to really gain their perspectives on the Serious Illness Conversation Guide, as well as what supported and got in the way of these conversations with their clinicians. And one of the main learnings from this qualitative work was that the Serious Illness Conversation Guide was acceptable, and participants reported that the open-ended questions were an improvement to the communication to which many were accustomed, which in and of itself really highlights the systemic inequities that exist in access to high-quality, person-centred conversations. We also learnt about changes to the conversation guide that were really important for the guide to be more inclusive and impactful. One example is a question that focuses on sources of strength, helps to develop rapport and demonstrates respect, and it also enables bringing in a faith and family into these discussions, which are really important in the communities in which this research took place. In addition to that, the conversation set-up and closing should emphasise non-abandonment. As part of this, we added 'I will be with you through this' at the close of the guide to demonstrate our continued relationship with patients and non-abandonment. And also providing communication about prognosis according to patients' preferences, with emphasis on a shared hope for a desired outcome really helps patients and families prepare for the future with their illness. This also links to some of the prognostic language that I had shared earlier about this idea of hoping for a shared outcome while also preparing for the future with potential changes.

**Visual**

**The next slide appears. The heading reads 'Research with African American patients, caregivers and community members'. There are three bullets listed below which Jo talks through.**

Audio

And so here's an example of a quote that came from this research. “Some doctors don’t know how to really talk to us… But if we, serious illness or not, if we consider these questions, we will have something on our side besides having nothing.”

**Visual**

**The next slide appears and there is a lilac rectangle with rounded corners in the middle of the screen. Inside it is a quote which Jo reads aloud.**

Audio

And so what we're building towards is a framework for what serious illness conversations, or conversations about what matters with patients, can do for people with serious illness and their family. And so we're learning that these conversations can help build trust and rapport; they can help us learn, as clinicians, about the patient and family and what matters to them, share information using compassionate language, respond to emotion, allowing silence, listening more than talking, especially using open-ended questions, and then being mindful and considerate of the timing, the setting and the patient and family context. This is really toward helping us really know patients as people and also know them in the context of their families and their communities.

**Visual**

**The next slide appears and has a heading which reads 'How can we address anxiety in these conversations?'. Beneath the heading is a list of bullet points which Jo talks through.**

Audio

And what can patients and families experience in these conversations? Feeling known, valued and respected as individuals, as people; heard and understood; getting emotional support, attention to and relief of anxiety and distress; feeling trust that their care team knows what's important to them and that what's important to them is driving their care; feeling informed and prepared for the future; feeling closer to their clinicians and empowered with a sense of control and agency to really set and achieve goals and to make plans for the future. And we're thinking about, in terms of these conversations — how can we ensure that patients feel known and cared for and cared about on their own terms?

**Visual**

**The next slide appears and has a heading which reads 'What do patients and families experience in these conversations?'. Beneath the heading is a list of bullet points which Jo talks through.**

Audio

And what are we learning about clinician experience? We have an epidemic of burnout, and this has been made worse by the COVID pandemic, and we have a long way to go to improve it, and there are many factors that are the root causes of burnout. We do know that moral distress and moral injury are highly prevalent in clinicians who care for people living with serious illness and that this has been linked to burnout and that this, in part, comes from feeling unable to prevent unnecessary suffering for patients and families and feelings of powerlessness to intervene. And so we have some descriptive data from our randomised trial in oncology to support the potential for meaningful conversations about what matters to patients to improve clinician experience and meaning at work. This is promising, but it needs more rigorous study. And so we found, for example, that 70 percent of oncology clinicians reported that their satisfaction in their role increased after using the structured approach to conversations about what matters. Nearly two-thirds reported that using the Serious Illness Conversation Guide helped their anxiety or improved their anxiety in having these discussions. And 82 percent of oncology clinicians reported that they would want a conversation using the Serious Illness Conversation Guide if they themselves had a serious illness. We also learnt from this work — this isn't featured here — but nearly 60 percent of patients that had this structured conversation reported enhanced closeness with their clinician.

**Visual**

**The next slide appears and has a heading which reads 'Oncology clinicians report increased satisfaction and improved anxiety'. Beneath the heading is a list of bullet points which Jo talks through.**

Audio

And so we've been gathering some narratives from clinicians about the impact that using the conversation guide has had on them and on their patients, and I'll give you a few examples. “The conversation took me about 15 minutes. In those 15 minutes, I feel like I learned a vast amount of information that humanised my patient and gave me a very clear idea of his wishes/fears/thoughts on the future. The patient and his family were much more at peace with decisions moving forward.” Another example from a primary care physician: “My experience with using the serious conversation guide is that it… opens the door for patients to feel comfortable sharing their feelings and emotions in the presence of family and their trusted provider.” And an oncology nurse shared that “These conversations create space for the unspeakable to be spoken, which alleviates a weight.” And when she talked about this, she talked about how it alleviated a weight not only for her patient but also for herself.

**Visual**

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And so what is the impact of these conversations on relationships and connection between patients, families and clinicians? This is one core area of future research for our programme. I think what we're learning is that interventions, training and system-level changes that truly prioritise relationship building, meaningful, respectful conversations have the potential to transform clinical practice, improve care quality and lead to positive experiences for patients with serious illness, those they love, as well as the clinicians who care for them. And so we just wanted to thank you for taking the time to watch this presentation, and we really look forward to discussing this with you in the question-and-answer period. Thank you.

**Visual**

**The next slide appears and the heading reads 'References'; an extensive number of references are listed below.**