Improving the cancer burden in multicultural communities

My name is she Sheetal Challum and I lead the Multicultural Strategic Program for Cancer Institute New South Wales. It's a pleasure to work with the institutes eviQ Ed team on a very important topic. How to develop language Resource for our multicultural communities and what are the best ways to disseminate it? We all know NSW is a very culturally diverse state and 30% off our population is born overseas. Cancer Institute New South Wales is serious about delivering good outcomes for the whole of the community, including our newly arrived refugee communities and long established migrant communities We know that are culturally and linguistically diverse. Communities faced several barriers in accessing cancer service's, such as they might be myths around cancer, lack of awareness. And, of course, there are language barriers to address. This we have screening. Resource is in 15 languages. They convey messages on the three pre national screening programmes such a bowel cancer screening, cervical screening and breast screening. We also know that when a person whose first language is not English is diagnosed with cancer, they had a long journey ahead to learn about how to develop. Resource is and co design the consumers and deliver a successful, culturally appropriate campaign the institute invited. Multicultural Health communication service is to share their learnings with us. This podcast is a recording off that forum. Hope you enjoy it. Rapid listening evidence based cancer learning on the go presented by eviQ education. My name is Lisa Woodland and I'm here with on some of the members of my team. Today I am the director of the New South Wales Multicultural Health Communications Service. We are a statewide service. We are hosted by one of the local health district's, which is Southeastern Sydney local health district. But we have a state wide remit and we work very closely with the Ministry of Health as well as the local health districts as well as the Cancer Institute of many of the pillars are really to enhance communication with culturally and linguistically diverse communities. So, like all parts of the health system, you know how goal, if you like, is to improve access to health information, improve access to healthcare, improve patient and provider experience and of course, ultimately to improve health outcomes, particularly for culturally and linguistically diverse communities in our case so really what I wanted to talk about very briefly with just some of our guiding principles and

concepts. So they include cultural responsiveness, health, literacy, co design and collaboration. We have a focus on safety and quality. We also do a lot of work in the space off health promotion and prevention. All of our work is about addressing health in equities are particularly working with vulnerable communities and new and emerging communities and using an arts in health approach. And I guess I wanted to really highlight this for you because when you work with us, when you commission us, when you engage us to do work with you, then we're not just bringing a technical service. We're bringing philosophy and a way of working that we feel really does enhance the outcome in terms of communicating with culturally and linguistically diverse communities. So we offer a range of service is just talk a little bit about some of them. So we have a value added translation service, which is what Jon will be speaking to you about today and again, I would just stress that this isn't a sort of technical, mechanical sort of procedure for us, this is really about enhancing communication. We also offer in language, multimedia resource development. So radio video, including Subtitling Voice over in language development of videos and social media clips and Rajan, will be talking a little bit about that today. We also offer a consultation and advice service, and I know that you've got the wonderful Sheetal who provides a lot of that, you know, resource to you as an organization. But we're also available at the end of the phone. to help us and problem solving to descend thinkings and brainstorming and offer our advice and support to you around any of these sorts of issues. At any time, you'll be aware that we run a lot of multicultural health campaigns and projects. And and I'm sure all of you are familiar with sort of one of the best known examples of us working together around the pink sari and when we do these campaigns. But also when we do translations, we also think about how to engaged media and social media platforms to really communicate to the community. So Jes we'll be talking about that a little bit later this morning. Consumer and stakeholder engagement, research and evaluation training in workforce development. So we're a small team, but we try and do a lot. We're very happy to work with you and your programs to bring those types of service is to you to help with your communication to the community. So I just talk a little bit more about the value added translation service before handing over to John. And I just wanted to highlight how this sort of relates to some of our guiding principles. So within that service, we arm do our coordinate focus groups to develop all refined messages, and this is really linked to that. That principle, if you like, of co design and collaboration, and we know that there's really strong evidence from mainstream health promotion programs and campaigns that they don't really reach a lot of multicultural

communities and communities don't recognize themselves. They don't think all this is for me. This doesn't apply to me that they're not reflected in the campaign. SoCo design and collaboration is a way off reaching out to communities to incorporate their voice in the development in the first place. I'll give a little example a little bit in a few minutes, but also I just wanted to talk about preparing English language materials for translation. So this relates to our approach in in terms of health literacy. So, like you, this is a very important aspect of our work. We would always ensure that we're writing for a reading age off 11 to 12 years and in plain English. And this'll is often where some of the tension comes in in terms of translation work. So as English language speakers we like to polish, we like to maybe add a bit of humor. We like to be a little bit clever in how we, you know, promote information. And when that translates into languages other than English, that falls very flat. And so there's a little bit of ego involved for us, says English language speakers. It's like, Well, that acronym is perfect and it took me three days to develop it, and it was like, Well, that means nothing in another language. So these are the sorts of things that we would like to communicate with you around along the way in developing translations, and we've all seen on social media where the English language has been mashed up and sort of translated from a language other than English into English, and we think that's a very funny. But we just have to be really aware. Let's not mash up other languages when we're trying to promote access to information and access to health care. It's wanted to talk a little bit about using NATI, accredited translators. And for us, this relates to our principle around equity. So we believe that the information that we provide that the health system provides to people from culturally and linguistically diverse backgrounds should to be of the same quality as the information we provide to English speakers. So we always use NATI, accredited translators. We don't use bilingual health professionals, and we don't use bilingual community workers. And that's because we can't assure that they have excellent proficiency in English and excellent proficiency in their language other than English and are skilled in that translation work. And look. These aren't necessarily hard and fast rules, but these are principles that we work with, and they have been some examples where we have developed information with bilingual health professionals, especially in the area of mental health, where, as you can imagine the translation off the concepts around mental health. Mental illness could be quite tricky, but if we developed up, um, information with the bilingual health professional, we would always get it checked by NATI accredited translator as well. So it's really about accuracy. That's really important because, as I said, that's an equity principal, New and emerging

communities. It's particularly hard to produce translated information and have that information check of moves on to the sort of community testing of translated materials as well. And this is relates to that sort of cultural responsiveness because, you know, translation there is a technical component to it. But we are translating not just into another language, but we're translating for the Australian community that speaks that language, and that's really important to remember. So, for example, we've been doing some translations around the Corona virus for Mandarin speakers into Chinese Simplified. We get it got advice from bilingual health professional that the word that was used for facemask, um, is technically correct. But it's not well understood in the community. And so it's that backwards and forwards that we need to be doing all the time because the end of the day. It's about the communication access to health information, access to health care. So if you caught up with us in some conversations that are around these sorts of tensions, you sort of know what we're aiming for and why some of these negotiations, if you like, need to happen. So I just thought I would spend like a minute giving you a little example of co design just to sort of give you a little bit of a flavor of it. So this is really where health professionals and consumers work together to create health messages. So this is sort of in the beginning process. If you like so. This relates to an example I was involved in in a few years ago, looking at cancer screening with six community, six language groups. So we worked with the Cancer Institute with Claire Gardener. She provide us with Well, what did The approved message is one of the tested messages from the Cancer Institute, and so that you know it's really important to stress the accuracy of the information. So that's their starting point. We then had a workshop with six communities, and what that looked like was about 40 50 people sitting at different tables in language groups. We presented some information on cancer screening to them because that's obviously really important. If they're co designing resources, we need to do that from an evidence space and then in language. Each of those groups discussed. Okay, Which of the most important messages What's worded? Well, what what? What might be changed? These are some of the messages provided by the Cancer Institute, and this is the result, if you like from the focus groups that did the co design that the community thought what's really important. And this was a sort of an unusual one, inasmuch as we were doing six communities at once. And as you can imagine, there were six different recommendations about what should say. So that was actually really important as well that once they did it in their small groups, we came back to a large group and then worked on what could all communities live with a bit of a difference between translated information and co designed

information. And they do have different purposes when we're looking at translated information that actually often really important that that comes from an English language base, which is accurate and we want We're looking at inclusive communication, so we want whatever is in English to be available across multiple languages, particularly with clinical information. That's not necessarily something you want to co design with the community who isn't necessarily as skilled and knowledgeable about those issues. So there's a really important place for translated information, and what we don't want to see is what we call orphin resources where something is translated into a language. It's not linked back to a series a suite of resources that are also in English because we know that English language resources are updated and checked all the time. We don't want these other resources floating around for a long time. They're not part of a suite of resources that have that review process. Often, we use CO design when we're looking at targeted information. So we have an idea about well ok, these are the communities we need to reach into for these purpose. We know that mainstream messaging doesn't work. We know that translated information doesn't really work with them, so we have to go back and involved in the first step when I started to think about how to begin this a little chat today. I reflected on the fact that my father, who smoked 40 cigarettes a day admitted this making 40 cigarettes they probably smoke, many more for at least 40 years died, unsurprisingly, off lung cancer. Even though he gave up smoking at 60 it the damage. A lot of the damage had been done on. My mother, who did not smoke, also died off of cancerous fluid collecting around the lungs, which was a secondary on. They were never able to clearly establish what which were. The primary was. It may have been lung. it may have been a ovarian and it may have been breast we don't know. And that's where I thought well here is. There's a kind of personal connection there. And then, as I thought about that, I've been I remembered that my foster grandmother also died of liver cancer. On that, my best friend from primary school died of stomach cancer at the age of 60, and the list keeps growing in that sort of shocking way, and it was the first time I've actually stopped to tally it up on. I'm sure if I asked, people here remember gonna do it, but to put up their hands if their lives have been touched in some way, you know, through their nearest and dearest by cancer, I think probably nearly every hand in the room would go up on that. The effect of that is it makes what we do, uh, if not personal, certainly important, important for everybody. And the unifying thing about all those relatives and friends that I mentioned is they were all of Anglo Celtic background. They were all reasonably well educated English was not only there first, but with the only language. So they had maximum access to available information. And so

that begs the question off. How much more difficult it is for people who have come to Australia, whose English is probably perfectly good for everyday transactions, the difficulties that they would face accessing medical information that that is important for their well being and indeed, the multicultural Health Communication Service, his own former director, Peter Ta Darrow We lost him in the same way he was forced into a really sort of quasi retirement. He always believed he would be back with us again, not to be and Peter, of course, was a highly fluid in both English and Italian. But as the sort of the darkness drew in towards the end of his life, he would, from time to time retreat to his original language. So there is that factor as well, that even even people who are decently competent in English need help when it comes to medical information in their own original language. And because new arrivals to this country, including refugees or even more dependent on organizations like the Cancer Institute being willing to put life saving information about early detection through screening and other initiatives. Front of mind, in a way, what you do and what well, what we try to help you do is create an intersection between science and marketing. The cancer institute has long set up shop at that crossroads. We are bringing necessary and potentially life saving information to as much of the population as we possibly can, and because of the cancer institute's experience in developing, brilliant resource is first in English. By the time your work gets to us for translation. An enormous amount of the heavy lifting has already been done in terms off making sure that the information is clear and concise. But it's even so through translation and other ways of reaching the broadest possible community it MHCS can facilitate the business of getting that message across by removing stumbling blocks and clearing a path to an audience with ideas on practical advice that human is. All of us are many people and nervous and even reluctant to here. But it's because we also work with organizations and individuals who are not as well tuned to the needs of that audience that MHCS has collectively recognizes the traps for young players. Primary primarily dealing with translators. We will seek the assistance off interpreters who are on the ground with that, you know, day to day knowledge of the community. Slang and euphemisms are a really obstacle. We'il probably have even witnessed in hospitals. Hospital staff asking patients, you know you want to go to the toilet. Your number one or number two is what that means to you without the rhyme off twos, on and on, but the other in the far too clinical Have you opened your bowels today Also have been present. When someone who's English wasn't their first language, we had to receive an injection that had to be administered to the bottom. Being asked on your tummy, please and all that. He was very conversing with the words stomach.

He had not encountered the word tummy. So just mentioned these things these the stuff that we take for granted that you know, all the alternative ways of expressing things and not necessarily part of our of the communities who are working with English, where English is their second language. So we don't want to make that mistake when we venture into their language languages that aren't alphabet based or just gonna fall apart when you get to that level. So kind of the takeaway from from some of that for me is, um, one. Is there an overriding idea about how you talk to communities outside? You're the main stream Anglo Celtic being that I came from, and I once had this expresses yet because don't patronize them and don't assume they know nothing. Communication, which is our business, is a two way street where people listen to one another when you get into some other languages Tamel is definitely one on, but there are plenty more great. Many languages are not as efficient as English English, like jam words together, it can use nouns as adjectives and verbs as nouns, so a great many other languages are, moreover, boast to, uh, tow up to about 25% more than English. So when I say it's the Space Age, let's use lots of space. I heard people who are creating things to make sure that there's a bit of room left because whatever fits beautifully in English is probably not going to fit so well in other languages. Translation isn't just about the words. The images are really, really important. This is from someone else's resource. It looks perfectly normal sort of photo. But when we went to the Arabic version, we were can consulted with the community who advised us that this sort of bare arms thing would not sit terribly comfortably with their audience. So we ended up using a different picture. Increasingly, we're going to be dealing with video and audio. Resource is, we're geared up for that. It won't replace the text with approach. It augments it and maybe begins a conversation that continues with the written word. My own view on this coming back to the communication idea is that whether it's written or in some other form, there's no problem. It's not like life. There is no problem that can't be fixed with time patients and goodwill, we can always we know we can always pick up the phone and talk to each other. And, you know, together we were able to drill down into the details because it's the details that matter. MHCS used to use a phrase have disappeared a bit from our, delivery, but I really like it. It was better health through better communication. And I just keep coming back to the point that communication goes in two directions. When you engage with communities, they will not ruin your perfect resource. They will hand you the very detail that you need to make it sing in a way that they can appreciate. And it may very well help you discover where the kind of roots of resistance to your message lie. this is Rajan, I'm the system manager here in

multicultural communication service. The most of the thing is we come across the a difficulty off people knowing what we What the right to use, whether it's ah video in language, target language to the English subtitle or video in the Target Language and subtitling Target language, which is the best for your audience. The Subtitling. It's always good for the social media because other people, when they're watching a video, they turned off the audio. So they read out, The majority of people are using social media. So that's where you need to consider, um, who's your audience when you have, Ah, video with a lot off graphic. So many text heavy texted and when you're putting a subtitling, you know, override the subtitle. One. appears. It'll always considered to use voice over rather than the subtitling in these subtitling, You always find it maximum of two line if you go more than two lines. People seem to be reading difficulties because of the following the line by line, so it preferred to be a two lines majority of the time. But some languages it's very hard to fit into it, very hard to fit in this of the lead channel and Arabic. It's a longer wording so In that time it need to be you need to be changed. A visual to match with it. There's a three type of voice over, down and under. Phrasing and lips sync dubbing. So what's the difference? Are down under. You can basically your original voice. It's in your background in the background and the translation on the second layer off it. So you still hear the background of the original audio, and around the top of it Phrasing Voiceover where the translation script carefully synchronized with the visual and the, voice over the lip sync, dubbing every frame off it. It's completely turn up the original audio on putting the translated voice When you selecting whether it is dubbing, I mean voiceover or subtitling, you need to consider what What is your content in your covering and how how you're planning to distribute publish to video. You know, without social media website. Because for the social media you need to consider subtitling, expect that text heavy need to consider what work for the text. heavy video. So for you, if you have ah ah graphical information info, graphic information, video Oh, then you need to consider voiceover rather than the subtitling. So then you need to look at the target audience. Thank you so much. Rajan and Lisa and John. I get to tell you the fun stuff I know about the website M H CS. All those health resource is that we have are in different languages over 500. Health resource is in 65 languages, so that's the kind of reach we have. And still they're emerging communities. So the way we work where John had said better health and better communication is yes, we do translations. Yes, we do. We have a website, but we also help developed campaigns and messages in ways that target the community because no, no message fits all. I'm Filipino. I have a Sri Lanken husband. I grew up in Papua New Guinea.

There's a lot of cultures that is in this room already. Language. Some of us may speak English, but we have a lot of in our families who speak another language or we have connections. So it's important for us to be able to develop our resources and our campaigns and messages that will actually reach the community. One of the campaigns that's been very successful with with our collaboration is the pink Sari campaign. And, yes, the message was increase breast screening rates with an Indian and Sri Lanken communities. But there's so much more behind that. A lot of the women don't want to share their stories because one it's just not. It's silence is important that they don't want to share it. And also there's this norm that if anyone knows where my family, my daughter might not get married. So there's so many myths. So we had to research that together with Cancer Institute and find out what's important. So there's evidence base, but we had to talk to community. And now Pink Sari. We also had to develop other stories are initiatives, innovative ways and trying to reach the community. We did a story telling story. It was a song writing competition. Now why would you bring breast cancer issue into storytelling or song writing? But in the end, a lot of people actually submitted their resource is their songs in different languages in South Asian languages and one who was an English speaker. One the song. But it was one. Let's put pink sari in them in the song that you're going to write and also what message? So it actually reached the community because not just one language, not just Indian and Sri Lanken community but all across. So that was how we targeted that message and we were able to win. And also what we do with that is we help collaborate with the communities in making sure that these stories are shared in media and the pink saris. Now pink Sari Inc has become on its own, which is never been done before where funded by a community after two years of funding. Now it's gone to the communities they're taking over, and they're doing bowel cancer screening and doing such a great job with it. And we're continually helping that. Um, the thing with M. H. C. S is when you're when we start working together, you're stuck with us, so we'll always continue helping you and you helping us. I think that's collaboration. We also did that 10,000 Italian Rose's campaign where 10,000. Why 10,000 Italian Roses. We co designed this with Italian Association 10,000 Italian roses because based on data, 10,000 women are not booking for breast greeting, not coming back or not booking. So we thought 10,000 Italian roses and roses is Rossi, which is pink and also ah key campaign for for it in Italy for breast cancer campaign. So we did that. We started working with the community. We went to Wollongong and we went regionally where the 10,000 Italian roses and it was really well accepted. And that's how collaboration works. We did it in language. She did. We

did this video in language as well as in English. And so it reached the communities. And then, of course, we went to the radio programs. We went to the television stations regionally and we got the messages across. So one of the campaigns, we do as well its life giving stories. This we're in this on 5th year. So we started with organ and tissue donation. How are you going to deliver organ? The message of death and life to communities and a lot of people don't want to talk about it. What? This at me? Organ and tissue donation. So we use storytelling in a way that helped tell stories from people. We What we did is we enlisted the help off William Yang and Annette Sha Wa and they're storytellers, power casts. And we we asked him to to deliver this message to help us deliver this campaign in a way that's unique. The processes is on stage, and a storyteller just talks and deliver the message. And when you listen to the stories about death and how how their stories have effective there lives an organ and tissue donation, you're gonna cry. And that's how you reach communities is when you tell stories and we try to do communication in a way that's different. That's unique. Doesn't have to. You don't want it to be okay, I'm telling you this, but just sharing the story and at the end off the story telling event. Everyone who comes out, I mean 99 let's say 95% they go out and say, Yes, I'm thinking about it. I didn't know that this is important, and I'm going to try to talk to my family about organ and tissue donation. So these are the kind of stories that you know has a fact. It's hard to talk about cancer. It's hard to talk about health. It's talking, decided to talk about life and death, and we try to work with the community and try to deliver it in a way that's going to be acceptable and unique. And we want to make sure that it's a arts and health approach. And finally, our very important campaign with Cancer Institute is a Shisha No thanks MHC s It's working with Southeastern City Local Health District Cancer Institute, leading the social media component of this campaign and. As Lisa and John had said, it's all about co design. It took a lot of, ah lot of focus groups to come up with messages. We went and talked to the young generation. The target group is 18 to 30 making sure that we do exactly what they want in terms of telling you not to smoke. Sheesha is going to reach the community, so we co designed it. We we developed message is making sure that the video and the resource is our effect. So this reached thousands and thousands of people and it was such it went viral and we're very pleased with the campaign and it's still going on. Western Sydney local health district came up with negative and positive, and it started conversations. And I think that's because of the co design work. We worked with the community, ensuring that they're hurt. And that's exactly what came out of this. And one beautiful thing came out. We received a letter from one of the community and said, We've my wife is pregnant and I

didn't know that Shisha was bad for us. So when I watched the video, I saw the campaign. I saw the way we took out the shisha and we threw it out and we couldn't have a baby for two years and we weren't gonna risk it and thank you for the campaign. So I think that's important for us to realize that their stories and we're reaching people and the work we do is reaching people. And we're storytellers and and we hope to continue that work with this is a production of the Cancer Institute NSW A pillar Organization of NSW Health,. More information, cancer.nsw.gov.au