## Fall Research Speaker Series: Community-Engaged Research BCcampus: Research Speaker Series, December 6, 2022 Guest speaker: Nadia Beyzaei Hosts: Gwen Nguyen and Leva Lee

#### LEVA LEE:

So good morning everyone. Welcome to our third and last session of the Fall Research Speaker Series. My name is Lena Lee, and I am learning and teaching manager at BCcampus. I'm very pleased to be welcoming you today from where I am on the traditional and unceded territories of Həndəminəm (Halkomelem) and Skwxwú7mesh (Squamish) speaking peoples, which are part of the lands of the Coast Salish, also known as Burnaby. If you wish, please share in the chat your introductions and place from where you're joining us. A few housekeeping items before we begin. The session will be recorded, so you are welcome to keep your cameras off and rename yourself to participant if you like. Live captioning has also been enabled. At the end of the session, we would like to invite you to participate in a short anonymous survey, and we will pop the link in the chat. This feedback will help us with planning future offerings for you. The goals of the Fall Research Speaker Series has been to provide opportunities for researchers and scholars to broaden knowledge and research skills in the B.C. post-secondary contexts, learn more about important current and emerging topics and research, be inspired to participate in research communities of practice, or explore themes in your studies or work, and to connect with academics and community members who share your interests. If you missed our first two sessions, please check out the recordings available on BCcampus website. I'd like to take a moment now to acknowledge the work of my wonderful colleague, Gwen Nguyen who partnered with me on this series of our IVC campus support team. Now, I'm so pleased to be able to introduce to you our speaker, Nadia Beyzaei on the topic of community engaged research. Nadia is a designer, researcher, and educator who works in the spaces of health and community engagement as manager of the Health Design Lab at Emily Carr University and is instructor in the faculty, is an instructor in the Faculty of Design and Dynamic Media. Today she will talk about two research initiatives co-lead by the Health Design Lab that highlight the importance of relational ways of working, de-centring the role of researchers. Welcome Nadia.

### NADIA BEYZAEI:

Thanks so much and thank you everyone for joining today. So I'll just share my screen here, and we'll get started. Okay. Hey, just checking that everyone sees the slides there. Is that working? Looks good, great. It sounds good. Okay, So it's my pleasure to be here today to share some of the work I'm involved in. through the Health Design Lab at Emily Carr University of Art and Design. So today I'll be talking about community-engaged research and how that shows up in the participatory design research we do here at HDL. And so. Here we go.

So as mentioned, I'm Nadia, I'm the sessional faculty in communication design and the manager of HDL. Health Design Lab is a research and design centre here. And we're located on the lands of the Musqueam, Squamish and Tsleil-Waututh peoples. And we really practice these land acknowledgments, not only as acts of recognition, but also as a reminder to attune ourselves to the real lived and material impacts of colonial ideologies. And I was born in Dubai and raised here in Vancouver. And my ancestry is of Iranian and Portuguese Indian descent. I started my post-secondary training with a bachelor of science at UBC in life science and mathematics, working in a health research space at B.C. Children's Hospital Research Institute. And later completed a master's of research in health care and design at the Royal College of Art while working here at the Health Design Lab at Emily Carr University in Vancouver. And I share this as my own heritage, upbringings, and educational exposure, like anyone's inherently informed the way I see the world and approach the work that I do.

So HDL is a research and design centre, as I mentioned, and we use what's called participatory design methods to catalyze and really amplify initiatives that address complex health challenges designed for us and is inherently collaborative. We never tend to work alone. HDL is dynamic team that adapts to meet our project and research needs. At our core, our team really includes a range of design students that come from our undergraduate, communication design, interaction design and industrial design, as well as master's program who we hire as research assistants. And projects are led by HDL staff like myself, design faculty, and research associates that we hire onto projects. And we really aim to form collaborative teams that where we work with external partners, whether that's health authorities or different community organizations. And it could be whether the non-profit or start-up sector as well as well as with other academic institutions. And through these partnerships on projects, we aim to foster new ideas, improve systems and services, and really amplify the voices and stories of people that we engage with. So common to all of our projects is the belief that we use design methods and mindsets to really engage people in initiatives that impact their lives. Whether that's research or quality improvement work, people with lived experience should be really at the forefront of those collaborations. And we think as designers and researchers can really help to support that.

Over the last several decades, there have been similar movements across health care, across research, and across design. From expert driven towards more patient and person-centred, people driven work. And there have been efforts like patient- oriented research and similar shifts have happened in the fields and practices of design towards human-centred and participatory design-based work. Where we're looking really from shifting for designing for, towards designing with and now designing by people. And I think it's one thing of importance to us is that we've really shifted from thinking about patient-centred or clinician-centred to patient- directed and allowing for people really to be engaged in that full trajectory of a project. To us at the Health Design Lab, co-design is a practice and a process that includes people who will be impacted by the design outcomes in that process. And that can include the use of creative and participatory methods to facilitate dialogue, ideation and the prototyping phase through testing and development of potential outcomes. And so to us, interviewing people or having them involved in user testing isn't necessarily co-design. So having a meeting with a multi-disciplinary group of people isn't really co-design. And so we actually prefer to use the word participatory design to describe our work, which involves creative methods. And we try to reserve co-design for projects that are really co-done in which people with lived experience are not just providing feedback or involved in key phases of a project, but they actually play a key role in decision-making and implementation. So today's, in today's presentation, I'm mostly going to use the word or term participatory design as it applies to all of our projects. While

some of them are on the scale of truly being co-design. But all or not. I think it's important to acknowledge this when something is truly co-design versus when we consider it more collaborative or participatory.

And so there are various levels of ways in which people can be included or participate in a project. And one way is not necessarily better than another. Different forms of participation are valid for different types of projects. In our view, co-design sits on the far end of this, as you can see, where people are making decisions and implementation and that side of things are in their hands. And if we're including people like key phases, we would generally refer to it as more of a collaboration so that the projects we share today are at various points in this kind of trajectory here.

So co-design and participatory design teams tend to work best with three parts. And so people with lived experience, professionals working with or for people with lived experience, often health professionals in our contexts. And provocateurs, which is designers and researchers. And that's our role. As provocateurs. We come to projects as outsiders, bringing our curiosity and a willingness to learn from the people we're working with. We bring ideas from across other contexts, as well as a way to re-imagine how things could be. We aim to challenge assumptions professionals may have through creative and participatory approaches and work to shift power dynamics and give voices to all of our participants.

As provocateurs, we use a range of participatory design methods and creative activities to support self-expression, story sharing, and dialogue. And we always use creative, aim to create new tools and activities for every project, which we'll see in some of the project examples that I'll share. We find that making is a very useful and an important tool when engaging with our co-designers. and participants in a project. This is where we can come in as an outsider and as design researchers and support people in sharing their knowledge and their stories. So these quotes from the BMC Health Services Research talks about how making is used to help codesign. Participants explore, reflect, and consider experiences, share, articulate, and express themselves and see how they compare and contrast with the experiences and perspectives of others. The use of making stems from the assumption that people in the process hold relevant the knowledge, but not the explicit sources of information. They are limited in the ways of expressing and communication. And many experiences and knowledge are tacit and embedded in the every day. Making as a tool can help level power hierarchies during workshops and research sessions, especially when all group members participate. When done well, it can be an incredibly rewarding way to contribute to a project and allow participants to feel really heard. With this context in mind, I'll share a little bit about the design approach on a few projects that we have that both incorporate making as core to the approach that we use.

In the context of today's session, I'll be sharing more community-engaged research, specifically in the spaces of addressing health inequities through immersion into culture and in an Indigenous- led project that aims to take a dialogue and making approach to cultural safety education, as well as another project that looks to shift the culture of care in a long-term care setting. And core to all of these projects is engaging people with lived experience using participatory methods and thinking about meaningfully sharing that knowledge back with people who participated and back in settings where others can learn in similar spaces like this. And so we'll dive into the first project after giving a little bit about the context of the Lab and the ways that we work.

So the first project is about decolonizing cultural safety education in the health care system through cultural immersion in Indigenous knowledge sharing and material practice. And the main question we've tried to tackle with this one is, how can we deconstruct racism in health care by really exploring a community-based model for cultural safety education that really uses material practice or making as a tool for that kind of dialogue.

The project emerged through the work and practice of an Indigenous and design team here at Emily Carr in close collaboration with the College of New Caledonia in Prince George, led by Marlene Erickson, who's the director of Aboriginal Programs there, as well as Brenda Crabtree, who's the director of Aboriginal Programs that Emily Carr University and special advisor to the president on Indigenous initiatives. And in addition to those core leads, we also had other critical people on the team who played a significant role as well as an Elder, Indigenous artists and designers. And an non-Indigenous family physician and an Indigenous nurse. Our team started this work more than three-and-a-half years ago with the idea of how arts and material practice could foster cultural safety. And the purpose of these workshops has been to further validate some insights that have come out from the In Plain Sight Report, where this diagram I'm about to share comes from.

In 2022 or sorry, in 2020, a review of Indigenous- specific racism in B.C. through a provincial health care system was conducted through the Ministry of Health. And the report indicated current widespread Indigenous- specific stereotyping, racism, and discrimination. And so it was clear from that that there was something lacking and we had to recognize the limitations of classrooms and clinical practice and teaching those pillars and find methods and approaches through a practical applied research approach to move health care providers to a place where they can integrate those learnings into their practice and hopefully contribute to long-term change over many decades.

And so our approach to cultural safety education is through cultural immersion in Indigenous knowledge sharing and knowledge practice. And I'll walk through a little bit of that approach and then later dive into what the role of design researchers were on the team.

So currently, most cultural safety education programs are developed specifically for health care practitioners or students. So we decided to really create a program that would bring health care students and Indigenous people together as co-participants. Really for the purpose of shared learning and mutual benefit. And key to the workshop experience has been the inclusion of local artists, Knowledge Holders, and cultural advisors. The workshop model included two-and-a-half day session up in Prince George. For COVID, we had to do a couple online, but two of them are at the Native French Centre up there. And we had approximately 20 participants where we really tried to strive for a balance of Indigenous community members and health care

students that were coming from the college. The two-and-a-half days were loosely structured, which heavily made up by the people who are involved in the room. Going from participants right through to the facilitators. And it was really impactful to have each core member play a different role during that time where if we did it in a different community with a different team, it would look completely different. And the core thing that was common though, is that we really wanted to work away from a teacher-student model and more about a community coming together for this work.

The concepts of embodied learning, brave spaces, and safe spaces where inherent are inherent within Indigenous knowledge sharing and really were the foundation of the work and the space that we were working into. Our team looked, took special care to build a local Indigenous protocol of respect. We tried to enable students to connect with real community members to hear everyday stories and experiences. And we found that this really helped to break down the prejudices and views on racism. And it wasn't through clicking through an online course or sitting with reading historical facts. It was about creating a safer space or brave spaces to have those difficult conversations and create those learning spaces that we feel like we can work with not only our heads, but with our hearts and through our bodies as well.

Within that learning space, there were three categories of methods that came out through this work that we wanted to highlight as part of the model. And those were hosting and convening, sharing circles, and making. And so I'll walk through a little bit of each of those shortly. I'll start off with hosting and convening. So we started the workshop with a brave space agreement, which was really an entry point to understanding Indigenous methodologies for dialogue and sharing. And were really important from a research perspective to make sure that we were creating a space where people felt safe to come into. And having the Indigenous team members and all of these parameters setup and even having the location of the workshop, when we could, outside of a hospital setting was really important in terms of the setup there. So these methods, methodologies were inherently aiming to create those spaces and allow for an entry point into the conversation. Bringing both Indigenous people and non-Indigenous participants together to allow for their perspectives and worldviews to really catalyze in a place where we were providing the contexts. And they were allowed to really connect with the community around and learn from people directly, rather than only as listing off facts or giving a slideshow.

Sharing circles were another method that was used. And so it created kind of structured periods of dialogue which were led by Indigenous hosts and team members. Everyone in the workshop sits in a circle and we take a turn to speak. And if you choose not to go, you can really just listen and pass on rather than respond to everyone else in the circle. And it was meant to just have a moment where everyone was present with the words and there wasn't a necessity to react right away, but rather sit with what was said. So inherently sharing circles are brave spaces. And that added to the layers of respect and looking to those Indigenous protocols of the team and the lands that we were on.

Making was the next core method out of the three. It offered participants both the space to rest and reflect on the sharing circle and those heavy conversations. That balance of making rest and reflection, structured and unstructured conversation, and created really the necessary conditions for introspection, learning, unlearning, and healing. And really allows for there to be an environment that stimulates dialogue in a different way than the sharing circle did. The participants could connect and learn from Indigenous artists as well as their peers through that shared experience. And it offered tangible connections to the land and traditional Indigenous practices. Their Knowledge Holders in their community. Learning about tanning hides with one of the artists sharing her experience with her mom and going through that. And then being able to make something directly from that hide that was made by the artist in her family was one example of that.

So the core thing about this was that the projects were not meant to be completed in the workshop. And so I mentioned earlier how making just allows for conversation to flow and for tacit knowledge to rise up to the surface. And so creating the artifacts was one element of the workshop, but really for the purpose of creating comfort and creating dialogue and less about completing the projects themselves.

Then the materials used in the making are really substantially linked to Indigenous cultures and ways of being and really contributed further to building that connection and community and place.

The Indigenous artists. The one who I'm showing here and teachers shared a deep knowledge that open dialogue between participants and built space for relationships to really strengthen and grow. And traditional practices like beadwork and caribou hide, toughening and rattle making sessions really created an environment to cathartically, really unpack and give relief to the heavier topics in the sharing circles. The lighter making here was moose hair toughening brings participants together through problem-solving and cultural, cultural sharing. While the drum making really took a tenacity that exhausts your body and yet brought the best laughter and stories. And so the flow of that really was intentional throughout the workshop and just wanted to share one quote from a nursing student who said, Doing the drum making ourselves is a whole new aspect. Because you learn it's not just about cultural safety, but by participating in it, you're learning cultural safety in a different way. It's not just hearing about it, you're doing it. Making really created an opportunity for many participants to connect with their culture and material practice. Resources that are hard to access, particularly in smaller communities.

And how that maybe connects back to the research aspect was Connie, who's the associate director of Aboriginal Programs and our collaborator on the project, mentioned to me at one point that she really views the role of researchers on the project as witnesses. So someone who is responsible for passing on the stories and histories they witness to others so that they are recorded in memory. And so for our in-person workshops, I transcribed notes and reflections onto Miro, which is a digital whiteboarding tool that you kinda see here and for two online workshops. We did this during the height of COVID, I was a live note-taker and took it on sticky notes. And this is an example of me sorting through and coming up with themes through that

gathering and synthesis process. And as part of this research process, we're reminded that those who participated in the workshop, we wanted to make sure we weren't capturing personal stories, that we wanted to treat that knowledge with respect. And rather than taking verbatim notes, it was really about just capturing the essence of each moment through our own lens. And so taking that kind of witnessing rule with a huge amount of responsibility and thinking about how do we then as designers and researchers, share that back with the community in a way that could provide some value.

And so I'm just sharing a couple of examples of how we looked at the ebb and flow of the workshops and the pacing and how the methods and approaches kinda came together to create that sense of cultural immersion where our Indigenous colleagues who are working in the space told us that intuitively they know that this happens. And for us it was just about how do we share that in a way that honours the work that they've already been doing in a respectful way.

And similarly, looking at the workshop model and what are the key elements around Indigenous ways of knowing that help create this sense of a safe and brave space and an embodied learning environment through these methods and looking at how that is cyclical rather than linear.

So in general, we really tried to challenge the epistemology of design methods and the role of designers and researchers on the team. Which really translates to other work at the policy and government level, as well as in research specifically. And so we thought of designers as researchers, as propellers. Giving, given the Indigenous material practice was a core aspect of the workshop experience. It was important that the Indigenous artists and leaders on our project team had the space and time to prioritize their efforts towards preparing material practice kits, which were a key aspect of creating a culturally immersive workshop experience. In order to create the space, there was a clear role for us as designers and researchers to support the peripheral aspects of the planning to propel the project forward. Throughout the pre-workshop planning, the workshop itself, and the post- workshop evaluation, our role was really about, it shifted and it blurred and it inhabited a coordinator role, a facilitator role, a communication designer role, an artist, and a participant in different ways. So it's really looking at just the way that the ebb and flow of the workshop was in terms of its structures. So was our roles as researchers on that project as well. Also looking at designers and researchers as conveners. So there's really an emerging role for researchers to take on that supportive role in amplifying the voices and skills of others, rather than first offering tools or methods to solve a design problem or research question. So an approach that embraces the diversity of the team and emphasizes the importance of really establishing relationships and allowing for values and goals to emerge and methodological approaches to be co-created in that space. Then lastly listed here is looking at researchers as documenters and synthesizers. So I shared that kind of image a little bit earlier as the sharing circle component of the workshop addressed difficult topics such as intergenerational trauma, racism, shame shared by experience of Indigenous people. The emotional impact of hearing and sharing those stories of lived experience is inherently harder for our Indigenous team members in that moment. And so given this

emotional workload being done by those team members, it was important for us non-Indigenous team members to take on the researcher role, to take on that witness rule as documenters and synthesizers and really help gather and share that knowledge back with the team. In general, in terms of that sharing piece, we thought about how might we create a suite of resources that enhance accessibility and reach of knowledge mobilization efforts. And we really, for this project, tried to take it almost three-tiered approach to that and think about how can we share that with academia, research, the government, at the local community level in Prince George, as well as the general public beyond the project, not only in the local community.

So we first did a research paper at the Design Research Society where we presented it in Bilbao in Spain, which really summarizes this work. And I'd be happy to share a link to that as well. And that was sharing it with design researcher colleagues.

We also wanted to make sure that we were giving back something to the community and the participants who were in the four workshops. We hosted an exhibit at the Two Rivers Gallery, which had artifacts from the workshops and the students who participated, as well as some quotes that came up through that research work of witnessing. And so one quote you can see there is that Making is the conduit of conversations. That's where the safety comes from. And so we really wanted to embody the experience of the workshop through making, through sharing circles and dialogue through this exhibit and allow for community members that were not necessarily only in the workshop to come to view this work and look at a different approach to cultural safety education.

Then lastly, we created a digital and print publication which really highlights the stories and conversations that were had in an editorial format mixed with poems, essays, photos, and quotes to complement the exhibit, but also sit as a standalone document and looking around knowledge sharing as something that doesn't only need to sit in a research paper format, but in a format and context and text layout that is more accessible to the general public and not written with jargon and written in lay terms. And so we were trying to think about who is the population, who are the groups that were trying to outreach to? And how can we make sure that we share this work beyond the three years of the project, but also beyond who participated from a team level as well as research participants. So right now what we're trying to do is think about how might we grow this project and this workshop model to create some connection with more communities. I maybe will wrap that project. And I think just to make sure I have time to share both, I might just keep going, but just keep a bookmark if you had any questions, maybe type them in the chat so that we can come back to them later. But I might just keep going and then we can have a chance to maybe compare or talk about both of the projects at the end.

So the next project that I'm going to share is called Come Alive. And it's a multi-year collaboration that we had with the Health Authority local in Vancouver. And this project started in 2018 with the key question of how can we shift the culture of care by uplifting the perspective of people living in care homes, creating space for them to shape the future of their

care. Long-term care has a history of being medicalized, institutionalized. This project looks at how we can shift to more social model of care. And so we worked collaboratively with people living in care homes, their families, and staff. And we'd been co- facilitating the Come Alive Culture Change Initiative with Vancouver Coastal Health through an emergent and collaborative process since 2018. This initiative explores ways in which participatory design methods can amplify the voices of people in care and their loved ones in order to drive organizational change.

This project began by bringing to light the rich stories, experiences, and aspirations of people living in long-term care. And through co-creative workshops. People in the care homes where reconnected with their personal histories, creating lived experiences, and their desires for the future.

We engaged directly with them to hear questions like what was important to them and actively listening and facilitating group conversations with our partners at the Health Authority and co-facilitating those sessions within the care home that people were living. And so we use visual prompts to engage participation and offer new ways for participants to share their thoughts and experiences. Asking participants to use photos and express, in this case, what good care looked like to them. And it being less about the photo that they selected and more about their interpretation of that. We intentionally used abstract selection of printouts to make sure that the dialogue that was happening in the room wasn't directed by the content, but really more immersive and tacit it in that way.

So during group conversations, the individuals in the care home were able to support and affirm each other's experiences and really created some bonds with others in the care home that they may not have known as well. And so these are just some photos from some of those sessions that were facilitated in a few of the care homes local in Vancouver.

And so from that, we were able to distill all of the information we heard into five key focus areas and guiding questions for the local health authority, a culture change strategy. And so the way that we did that with putting sticky notes on the wall, just synthesizing all of the information and doing some affinity mapping to gather and let these themes come up. And so some of the themes were recognizing and supporting ability, acknowledging that people in the care home really want to have a sense of purpose. And of course, relationships and conversations being an important one. But also having individual needs and care And for staff members to really acknowledge that. I think key to shifting away from that institutional model was thinking about flexibility and spontaneity and looking less about having each day scheduled by times of things that were happening before lunch, during, and after and more around allowing for different activities or engagements with community to happen that way.

And so we created a film, short one, to share back those five key areas and voices of people in long-term care directly with the staff. And this video was then used as a tool to facilitate additional workshops and conversations. I'll later on share this link in the chat so that everyone has some of the resources and you can take a look a bit later. But it really was meant to kind of

support staff in the care home and allow for them to pick a theme and figure out what felt like one they wanted to allow for more dialogue to happen within that care home and find ways that they could add spontaneity or that they could support building relationships. And so it was the tool to catalyze those conversations. Yeah, That's one's a snippet from there.

So from there, we had a 100-person event in fall 2019. This was right before we, the pandemic was impending and we could still have 100 people in a room. And we shared the video with staff and then engaged them in activities around culture change. And we started by elevating and sharing the voices of the people in the care home and then engaging staff in dialogue because their perspective is also critical in culture shift. Using a metaphor is a tree to facilitate the dialogue. Understanding the roots of a home, thinking about what is immediate, an imperative to envisioning what would grow and what dreams could exist, and some blue-sky thinking related to that.

These are some photos of Van Dusen with lots of tables and facilitation and us walking through those conversations. And actually I'm just in the Lab today. So in the other room, we still have all of the trees up on the wall as a reminder of that session that we had. That session led to the co-designing of a game that could then be used. Again once returning to people living in care and talk about and elicit further insights with them. And so this was just a process of how to use that toolkit. This game was used sensory objects as conduits for conversation with each object, evoking memories through tactile and visual reminders of past memories and experiences. And it was really meant to just be used as prompts similar to the photos were used in that other research generation activity where this one was more for connecting and relationship building.

These objects really helped drive those conversations and lead to further insights about how different experiences at the long-term care home could affect people. On screen are some objects that were included in those kids.

So here's one example of people in the care home being invited to play with, play with and prototype the game and shape its flow and use. And so then in March 2020, when COVID hit, it really hit long-term care homes really hard as it did for the rest of the world. And we had to pause and pivot our approach and direction for the project. And so we, we really work to find accessible methods of participation and co-creation that would happen during virtual workshops. And recognizing that access to people in long-term care home wasn't possible and staff were currently burnt out in those settings. Our team looked at how we could contribute to that and support that setting. So we recognized that the restrictions to visitations were extremely hard on people in care and their families. And so we work together ideas from family members to share with them about how to connect in the best way given the current restraints.

And so in this setting, as researchers, what we did was set up workshop activities on Miro, the same platform I'd used previously for synthesizing the research information or that was witnessed in the cultural safety education workshops. This time we were using it as a facilitation tool to really create a map or a base for a workshop activity and allow for

conversation to happen over Zoom, and in this case, ideate around ideas of how people could best connect with their family members.

So I just wanted to wrap, I think, this part of the session by really sharing and saying a few key points about participatory design that could be applicable to both projects. A lot of time we focus on talking about co-design workshops and methods. But I really want to emphasize that in the work that we do at the Health Design Lab, those actual workshops are very important, but very small amounts of the actual work that's involved on it. So doing participatory design research in context with community requires a ton of front- and back-end work. So I've highlighted the workshops there, but also wanted to show that before and after forming the team relationship-building data management and making sure that we're sharing back knowledge with people is actually a core and big part of the project. And almost the iceberg underneath the water line in the ways that we work.

In her book *Beyond Sticky Notes*, K. A. McKercher speaks about four key principles of co-design. The first is about sharing power and ensuring that power is distributed to people with lived experience. Second, it's about prioritizing relationships before jumping into a project towards an outcome, time and attention is really required to build a team and so to bring the right people to the table and to establish trust. That's really core. Third, co-design provides many ways for people to take part and express themselves. And so e.g. through visual or kinesthetic or oral approaches, instead of relying on writing, slideshows, and long reports. And so participatory design and approaches aren't about relaying information, they're about facilitating self-discovery and moving people from participants to active partners. And finally, co-design should build capacity as designers on a project. We view our role as helping to support the organizations that we work with and adapting new ways of being and doing an engaging people with lived experience and building capacity for people with lived experience to be part of the design and research contributions as well.

So our projects, other projects that we are involved in may share some of these values. But what may be less common is the use of methods to support patient or public engagement and collaboration with your research participants. So I just wanted to conclude by summarizing some of the benefits that making can bring. And so by engaging with people with lived experience, we find that people are capable, ready, and excited to be engaged with these methods and in research. They can support their engagement in ways beyond interviews and conversations.

Thank you so much for listening to me. And I pleased to open the room to some dialogue now to talk about either the projects or the Lab in general. And thanks so much for your attention. Great. And I've just, there's some links there as well. So if you're curious at checking out our website or looking at us on social media, those links there are available and I'll make sure to add the ones that I mentioned during the presentation. Thanks.

LEVA:

Thank you, Nadia. We'd like to open the floor to see if you have any questions. So if you'd like to unmute your mic, if you have a question or raise your hand or pop something in the chat. There is one now.

### PARTICIPANT:

Hi. I'm just, it was an excellent presentation. Thank you. I learned so much. I think I need to view it a couple of more times before I get all the message. I'm wondering if I was really curious. I had done a visual methodology approach myself. I found them very powerful and in the one where you used, where the pictures and you evoked from the participants their thoughts about care. Did you rely on any previous visual methodology literature? Is there anything you can point to where. Was this designed just by you and your cohorts?

### NADIA:

Yeah, great question. So I would say, I almost probably have it. I'll show you right now it's on our bookshelf. If you're curious about learning a little bit more about these approaches. This is a fabulous book called Convivial Toolbox, and it's by Elizabeth Sanders. And so within that, that's almost like one of the core books that we use at Emily Carr to teach design research and it really talks about using imagery, as well as collages, and other method and approach. And it really allows for different ways of facilitating dialogue through photos is one example. Asking people to collage or make with clay or different approaches could be appropriate for different settings. And so we've definitely took that from different settings and allowed it to, maybe crafted it with the team in terms of what type of visual language or what photos specifically we wanted to use for the project. And engage with the partners of what they thought would be good visual language or approaches they thought were appropriate. And so we adapted some of the things from this book and then crafted specifically for the project, but inherently the use of photos. Yeah. It's something within design research.

### LEVA:

Thanks for the question, Brenda. Nadia, there's one in the chat about research ethics. So Jamie Jones would like to know how you approached research ethics in these projects.

NADIA: Great, excellent question and definitely something that I was talking about. There's a lot of work that happens beyond just the workshop. And research ethics is a huge thing on the front end that we've had to do actually for both of those projects and the one with the Health Authority, that one locally had to go through UBC actually first, just because that covers people within the care home. And then came to Emily Carr afterwards. And it was, I think one of those conversations that's happening more commonly within long-term care settings is making sure that ethics boards allow for people to participate in those settings. And there's always that question around capacity to participate. And I think there's a struggle sometimes with people of how do you define capacity for older adults. And I think we really try to say this type of research is necessary and show that, yes, they do have capacity. Their voice needs to be heard in order to do this type of project, we need research ethics, and we're engaging people in an appropriate way to share their knowledge and gather it from multiple different sites and find tools that allow for people to express themselves. So I think that was one thing that was key to articulate in that research project in a way that we made sure we hit the research risk matrix that you have to fill out. I think it was just a lot of back-and-forth around what is the actual research part of the project and which part is maybe quality improvement and really defining those for that project. In terms of the Indigenous project. We had to go through the college that we were recruiting students from, the College of New Caledonia first and then actually go through and multi-jurisdictional review at Emily Carr. I think the main one for that was just again, separating out what was the research part of that project and the methods associated with it and which were elements of creating community. And that took a lot of back-and-forth of how to articulate it, of what would be archived or what would be research data and how would that be stored? And OCAP and all of those principles and I think it was really around we, us as a team honouring the local protocols of our team and Indigenous leaders in Prince George and allowing for them to direct the direction of the project, and writing that into the application process. The other piece I think too, was doing the TCPS 2 Core Ethics Tutorial and recognizing with the research ethics board of when it was appropriate to ask for our research assistants and as non-Indigenous team members to of course, have that as we do for other projects, but not ask Elders or Indigenous leaders or artists to do that in as they're coming with their expert knowledge and Indigenous ways of knowing. And the research component really was almost a back seat to the workshops that we were invited to or helping to convene and propel. Yeah. I hope that helped to answer your question, Jamie.

### LEVA:

Thanks. And maybe you could take a peek at the chat. Some great comments about the research, the catch-22 situation that you're in with regard to the research ethics review board usually wants to know what you're gonna do, but often you don't know if it's going to be emergence. And yeah. Yeah, I think one thing we've noticed that Emily Carr, which I think in some ways because we are in an art and design university, those who are on our boards are faculty members or other people who are used to this emergent space. And so we're able to meet and have dialogue around. We're not overly defining exactly every step of the process, but really being more open with we're going to run a workshop. We're going to try to approach generally these larger questions, generally through these types of methods, rather than having a minute-by-minute script. So there's some flexibility that we've noticed and allowing for there to be dialogue. I think with the research ethics board and show that there is safety, even though there is emergence and the two don't need to necessarily be clashing.

### LEVA:

I had a question, Nadia, and that was that in your projects, you had great participation like the numbers, and I was wondering what's your secret sauce or is it how you invite people?

#### NADIA:

A huge thing I think along with what happens outside of the workshop is recruitment. And so much attention I think out of my experience of doing research for the past 10 years, recruitment is one of the most key things in any research project. It informs the direction of how whatever data that you have comes out of it. And so if you don't have a representative

population or you're not making efforts to make sure that it's inclusive or diverse then whatever you have at the end inherently won't be useful for a broader audience. I think spending more time with recruitment. In our cases, what we've found is really valuable is when we're working directly with communities, rather than us trying to put out an open call of people to participate, we really tried to find organizations that are already have a network of people and really try to build a relationship with them and allow us to collectively look at their network for mutual benefit and exchange of knowledge that way. And so for example, for the Indigenous project in Prince George, we had a nursing student who is in the program. She had students who were in classrooms with her. And so it was easier to have her be the one supporting with recruitment and doing that local in Prince George's and for us to try to do it in Vancouver remotely. Then for the one in the care home, I think directly engaging with staff and the rec therapy staff was really important in that setting where we were going to them rather than asking participants to come to us. And I think that's a huge one for recruitment where if you meet people where they already are, whatever setting it could be, then you're more likely to see engagement and not disrupt someone who has a family and kids and trying to run around and make it to your session. But really if you're meeting them at a group that they already attend and somehow there's a relationship between the project you're involved in, then you have a better chance of, I think, have a broader depth of people and involvement. But also number as well.

### LEVA:

Thank you, That's great. That's great. Pablo has a question. Do you go into research with research questions already in mind and then amend as necessary or are research questions entirely co-created and emergent from participants or community members.

### NADIA:

Great question. And I think Emily Carr or the Lab, at Emily Carr is quite unique in the sense that in some ways we operate like a consultancy where we hire and we have clients where we create a contract. And so in some ways we need to create some parameters of the ways that we're working where that was for that Long-Term Care Project. That was the case. Where if for the Indigenous Project that was a grant we applied through Vancouver Foundation. And so the research question in those pieces were articulated in the grant. But typically we like to start with the how might kind of question to give an overarching kind of scope to the type of work that we're doing. But it's loose enough that it's really not granular and it is emergent. So we like to start somewhere, but inherently it changes and the how might we questions I shared it on the slide were definitely not the ones that I started, we started with at the start of each of those projects. Question about Miro.

### NADIA:

Yeah. And so I feel at some point I should be as spokesperson for Miro, but I'm also someone who digitally I enjoy those types of software where we definitely have had people who are not into it at all as well. So I think it really depends on your affinity. In terms of pros, I think if you're comfortable with it for yourself as a researcher, it's a great way to document workshops. And we on a different project, we use reflexive thematic analysis as a method for synthesizing. And

so we really took like, as you saw that photo of like sticky notes up on a board in Miro, we really captured a thought in each sticky note and were able to sort on Miro, and in some ways was a lot better than trying to do it up on a wall at the Health Design Lab where once we take it down, it doesn't exist anywhere. And you could copy the boards and try different ways of sorting where you would never do that with sticky notes, where you're going to write them four times out. In terms of a synthesizing tool, I think it works really well. In terms of data capture and trying out different ways of sorting information. As a con, I will say because there is a learning curve to the tools, I wouldn't ask people to contribute their responses through Miro. It would be if your team is facilitating it and you're guiding through and just asking people to contribute to dialogue. And you have a team behind who is typing out are working on that. It's useful there, but it definitely can be a distraction or people getting frustrated with the platform and not focusing maybe at the question you're trying to generate content around, but really then focusing on their struggles with trying to get the sticky note on the board or the arrow in the right spot. And so I think in that sense it's good with the trained group of people for capturing information. But I wouldn't necessarily ask participants in a moment to, on the fly get up to speed in five minutes.

### LEVA:

Okay. Thank you. Thank you for that. We probably have time just for a couple of more questions. I think Jamie has had her hand up for a bit here, so maybe Jamie, would you like to I have a question.

### PARTICIPANT:

Yeah. I'll just speak into it. It's just elaborating more on the research ethics piece because we have a research team that's working through a similar experience. And I'm really curious thinking about your cultural safety project. When you have the workshop, when you did the consent form. And then also I saw you shared a bunch of quotes and pieces like that and your end product. And so just that fine line between research and publishing and when to do it, when it's a workshop and participatory. If you could just give us a little bit more concrete examples of your process, I would be so helpful. Yeah, for sure. And so that one, what we have found helpful is consent forms, if you just have a printout and you put it on chairs, it feels very intimidating and it makes it feel very much like we're in a research space and people would just kinda know that it gets rattled off and it changes the mood or vibe of the room. And so what we've done instead for that project was we knew it was around making and that was the goal of the project. So we actually in the first 10 pages of a design booklet that we put kind of walking through each making activity and how you could do that at home. Then we had a page at the end that was the consent form and a contact form and some other things. And so we had emailed it to them prior to the workshop as a PDF the entire booklet so that they had a chance to read over. But in the session itself, we made sure that it was on every chair in the sharing circle so that when we introduced the project and went through the more exciting intro bits, then we got to the consent piece where it was like, oh yeah, by the way, let's just have a moment to kinda go through this together one last time. And we actually cut it out of the book and then took a photo from our team and if people wanted it back, we would give it back to them. So that was a kind of our strategy of making it feel like it was blended with the rest of the strategy and not a stand-alone piece. And so that was shared by email beforehand and then in a booklet. Thank you.

## LEVA:

I think Brenda Davis has a question. Did you publish an article about your research process and outcomes in the long-term care research that you talked about?

# NADIA:

Yes. And so if you go to the healthdesignlab.ca, there's a Read tab, and so we have all our articles for different projects there. And so you can find them for the Indigenous one, for the culture of care one, and there's a few there. So I'll just post that link there and you can take a peak and there's a Read tab on there with the links.

# LEVA:

There's so much, so much we can learn from you, Nadia, but we've run out of time. So if others have questions, you can certainly put them in the chat and maybe we could follow up with you after. But it is now one minute after noon. Don't want to keep people from their lunch. But I do want to say, thank you so much for sharing with us your amazing work at Emily Carr and such exciting ideas and approaches for community- engaged research. I know I found it so fascinating and informative and really so inspirational. So thank you so much. We've popped the survey link in the chat for your feedback for the Research Speaker Series. And we really thank you all for joining us today. Next year, we are looking forward to offering three more Research Speaker, sessions for you. And they are planned and so we hope you all watch out for the information about that in the coming year and that you will also join us. So thank you very much and we hope you all have a wonderful day. Thanks, everyone.