

Hopkins Hour Live Event Transcript 20 May 2020



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[Onscreen: PowerPoint screen welcoming attendees to Hopkins hour, presented by The Dignity Project Research team, about The Dignity Project and engaging consumers as citizen scientists]

[Onscreen: Kelsey Chapman, Researcher, The Hopkins Centre, Griffith University]

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Hi everybody, we are going to get started. Welcome to the first Hopkins Hour in a virtual environment. We hope you're all doing well given the current challenges presented by COVID-19. We would like to extend a warm welcome to all of our external partners, stakeholders, our subscribers and Hopkins center members who are joining us today. Hopkins hours are typically limited to only Hopkins Center members, so we're really excited that this is one of the first events, we are able to extend to a broader audience. Obviously, this is a pilot of this Microsoft teams live platform for us, so if there are some technical difficulties, please bare with us.

Before we begin today's proceedings, I would like to acknowledge the Traditional Owners of the land on which we meet virtually today. My home office is on the land of the Bundjalung people and I would like to pay my respects to the Elders past, present and emerging. We encourage all attendees to research the Traditional Owners of the land on which they live and work. However, we also acknowledge that the interactive maps to do this are not accessible for all.

For those of you who don't know me, I'm Kelsey Chapman, a member of The Dignity Project research team and a PhD candidate at The Hopkins Center. I am your host for today and I'm joined by some of my esteemed colleagues, Professor Elizabeth Kendall and Angel Dixon, and we also have a couple of other people who will be manning our chat and question function.

Just a few housekeeping items, if you do experience technical difficulties, please feel free to put a question in the Q&A function, which is on our right toolbar. Macarla Kerr has put up a few reminders for people in there and one of our team members will try to assist you if possible. Internet connections obviously will vary in this environment. There may be a

delay, they say between 7 and 10 seconds, or it could be more. For you on your end, it is seamless, so although you might be on a delay, it should not buffer to the current time frame, so you won't miss anything. If you do have technical trouble or need to leave the event, we are recording, so feel free to do so. You can also pause at anytime, without losing your place. We are going to distribute the full recording in the coming days, so you'll have access to that. There will be an opportunity to ask questions throughout the presentation using that Q&A function I mentioned, which should be on the right hand side of your screen. The questions will be moderated by our team and will address them at the end of the presentation. To post your question, just click into the Q&A function, enter your name or you can also stay anonymous if you wish to do so. Your question will be sent to our event moderator, which is the lovely Macarla Kerr, for those of you who know her, and we will publish them and address them at the end.

Without further ado, I would like to start by introducing The Hopkins Center Executive Director Elizabeth Kendall and she's going to start off the presentation by speaking about citizen science and its importance to the Hopkins Center.

[Onscreen: Professor Elizabeth Kendall, Executive Director, The Hopkins Centre, Griffith University]

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Thank you, Kelsey. Please let me know if anyone can't see or hear me, it's the most strange experience talking into a computer and not to real people, so I know you're out there. Now what I get the pleasure of doing is introducing Kelsey and Angel to talk about the really important project that they're running called The Dignity Project. So I just wanted to take it back a few steps, and talk a little bit about citizen science and what it is. It's this wonderful term and some people say that it's a bit of an oxymoron in that they contradict each other. Surely you can't be a citizen and a scientist, but because they are incompatible, but in fact they are not. All scientists are citizens and citizens can be scientists and use a scientific way of thinking. Science itself isn't really as subjective and removed from the real world as we like to think it is. It definitely has as one of its objectives the scientific method, which is keeping as many things as constant as possible, so that we can determine what's going on. But this sort of rigor doesn't prevent citizens from being scientists.

Citizen scientists is usually defined, as the engagement of the public in the collection and analysis of data. That level of engagement can range from systematically collecting data under the supervision of a scientist, right through to driving research projects themselves and engaging scientists when they need, rather than the other way around. This sort of model of science tends to happen in the natural and environmental sciences, where citizens contribute to things like the discovery of new species or new stars or the monitoring of environments and animals and the degradation of the environment. It sounds a bit like a new and innovative concept, but it's actually a really old practice and many of the most famous scientists throughout history, would actually be called Citizen Scientists. They were self-funded and they were driving their own discovery agenda and then contributing to community as a result of the knowledge that they produced. But there was this period in time, when so called 'real science' became the work of universities. It would become removed from community and relatively inaccessible to the general population. So what we're seeing now, is a movement back towards citizen science and it's driven by several trends that are pretty important. There is a demand that raised up in the 70s and 80s to

really democratize science, give it back to the community and build civic trust in science and scientific knowledge again. But there's also a very pragmatic driver and that's the fact that, funding restrictions mean that scientists simply can't do everything and they can't be everywhere and they need more capacity to collect large samples and to observe the phenomena at all time and citizens can do that and contribute to real knowledge. The real growth though in citizen Science has come through the increased access to powerful home community computing and connectivity. Which is really allowed every citizen to use amazing tools like GIS or satellite data or advanced analytical software. There's a little subtle trend in the background though, that drives us towards citizen science, in marketing and retail for instance there's been a growth of what's called 'Consumer Science'. It's research that's really aimed at understanding the decision making and experience of service users, people who buy the products, that people design. This type of research is often being done by marketing companies, but there's been realization in recent times that the customers themselves might actually be best placed to inform on product and service improvement. And this is the trend, that's of most interest to us.

In the disability sector, we've had this very long and shameful history of experts doing things to people. Taking information, producing knowledge, but not really returning much to the community and to the people who've been affected by that knowledge. Research is knowledge. It's knowledge that should be enlightening and empowering. Unfortunately though, research has a history of being a major contributor to the suppression of people with disabilities, as it has been to our first peoples, in Australia particularly. In the area of disability, we see citizen science as an important shift for research towards recognition that people with disabilities are actually experts in the nature of their own experience and that people with disabilities as the users of the services that we produce, have the best knowledge about how those services should be, what they should look like. We have such a large body of health services and disability research, that's driven by practitioners or academics, and not as much that's driven by people themselves, citizens with disabilities.

Some of the largest gains in the disability sector have been made by citizens with disabilities coming together and the mantra that you'll hear all the time is, 'nothing about us without us'. That mantra has driven some of the most fundamental shifts in disability service provision that have ever been seen. So it is very very important and it's an important element of gaining true control, and engagement in research is really important to that.

Our aim at The Hopkin Center is to increase the involvement of consumers in our research, at all levels, to the point were in the future it becomes just common practice for our researchers to know that they will be working with people with disabilities, and that researchers with disabilities may well be driving the projects, that they are engaged in. So it was from this sort of backdrop that we decided to apply for a small citizen science grant and we weren't expecting to win it and we did. What was really exciting, was that we were the only project that won a citizen science grant, that wasn't focused on animals or insects or something to do with nature. So the topic of our citizen science project is dignity. The importance of this topic just can't be underestimated. I want to thank Kelsey, Angel and Kevin, who has also been working with the team and Macarla, for taking this project forward. It's been such an important project and it really has the capacity to change the way we think about the services that at we deliver and the products that we design.

You may have recently heard of a terrible case in South Australia. A woman with cerebral palsy who died, I think it was just last month maybe, of severe septic shock, multiple organ

failure, pressure sores all over her and malnutrition. This was after being stuck in a cane chair for 24 hours a day for over a year, because no one bothered to provide the right sort of services. That's undignified. That should not happen in this society, in this age and that is really what the dignity project is about. Hopefully not all that extreme in cases, but those cases still happen today. The Dignity Project is about improving the way we think about the dignity of people with disabilities and who best to hear that from but people with disabilities themselves. So what I will do now after that short introduction, is hand back to Kelsey, who is really completing her PhD on this topic as well, and is the best source of knowledge about this project, so thank you Kelsey.

[Onscreen: Kelsey Chapman, Researcher, The Hopkins Centre, Griffith University]

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Thanks Elizabeth and thanks for that great introduction. I think part of what's so exciting for us as the dignity project research team, is what was Elizabeth has spoken about, is that this is a bit of an exciting and new territory that we are crossing into. As researchers, Angel and I are both certainly early career researchers, setting out on this exploration, this pilot project, so it has been really exciting. Just to elaborate a little bit on what Elizabeth has started to talk about with 'why' dignity. It is something that we get asked frequently, what's so great about dignity, what's so important about it. I think inherently, we all know why it is so important. But to give it a bit of context, the United Nations convention on the rights of persons with disability brought together disability and dignity in the context of human rights. It's as we all know a landmark international policy and legislation framework. It's one of the first human rights frameworks that was developed by people with disability for people with disability. Dignity in the context of the CRPD is referred to as inherent dignity, something that is universally applied to all human beings, regardless of their capabilities, citizenship, functionalities. It's this landmark that paved provided a pathway for exploring what dignity might mean for people with disability and how it might differ from typical conceptions and understandings of both dignity and disability. Australia ratified the CRPD in 2008 and the following year the national people with disabilities care council and care council released their shutout report. This was quite a significant document that highlighted the ways in which people with disability felt the aims and articles of the CRPD were not yet being realized in daily life for people in Australia. It also provided recommendations for enacting the principles in policy in daily life. The flow on effects from the shutout report was the creation of the national disability strategy, which hasn't been led to the NDIS and all of the other radical reforms that have come out of it. Underpinning that national disability strategy specifically is the mention of dignity and nondiscrimination for people with disability So it's there in all of our underpinning legislation, but what does it actually mean. More than 10 years on from the ratification of the CRPD in the shutout report, the daily reality for Australians with disability, is still one of exclusion, marginalization and indignity. The same problems that existed then, exist today.

The Australian Human Rights Commission receives 44% of its lodged complaints under the disability discrimination act. And people with disability continue to experience poor help with 42% of people in Australia with a disability assessing their health as poor or fair. The current times of economic austerity and pandemic only serves to increase those disparities and barriers as resources and funding gaps increase and participation and opportunity and isolation are becoming the norm.

Despite the fact that dignity isn't underpinning concept mentioned throughout our policies and frameworks. It's a concept that is difficult to define and understand, that more so I think although it's a commonplace term. We know what undignified treatment looks like and feels like, but we don't actually where it's difficult to articulate what dignified treatment looks like and what dignity feels like. Research is currently being done across a number of different spheres, including palliative care, dementia care, and age care about dignity. Again if focuses primarily on what's undignified or tenants and models of dignity which are difficult to translate into practical application and meaningful experience. For people with disability dignity is integral to maintaining all aspects of human rights and increasing accessibility. It has physical, emotional and mental health benefits. While a loss of dignity and undignified treatment, has severe health consequences. People who feel they are treated with dignity, report feeling safe, happy, in control, valued and having an overall sense of general well being. Conversely people who are treated without dignity, report feeling fearful, humiliated, anxious, threatened, insecure and often helpless.

This research, the dignity project, using citizen science methods aims to pilot citizen science research by embedding people with disability in our research team, as Elizabeth said and using the methods to collect data from people with disability, in order to develop an understanding of what dignity means for people with disability, how it's experienced, how it's lost and how it can be protected. For us, we view a couple of ways that citizen science research can be conducted, as Elizabeth alluded to. It's either for the people with the people or by the people. For us we feel we are piloting a citizen science research framework that is both with the people and by the people and that is something that's extremely important to us. I'm just going to put up a slide.

[Onscreen: PowerPoint slide]

[Audio: Kelsey Chapman, Researcher, The Hopkins Centre, Griffith University]

What does slide highlights, is a framework that Angel, I, and the Dignity Project Research team are currently piloting. The way we're doing that is through a survey, through the Metro South Health consultation hub. This particular platform is really interesting in that it allows people to answer the survey questions in the method that they're most comfortable with. So by uploading and video or audio recording, they can type out their responses in a word document and upload that and they can also just answer it straight into the text space provided. We're also collecting data and building the big section that's really important to us, which were calling the Dignity Project Community Hub. This is a SharePoint platform. It's a safe space for people with disability to come together, to analyze recontextualize and discuss what do you mean to them and what it looks like in daily life. Angel is going to be discussing that further in detail. We will also be holding a focus group with citizen scientists', key stakeholders, and academics, later in the year, hopefully we can do that in person and not virtually. Let's see what's happening with COVID. This focus group is going to help analyze the data from the survey. I think it's important to mention that this is only our phase one. Our hope for the dignity project, is to build a sustainable research stream that examines dignity, theories of recognition, dignity in different spheres, how defects health status, mobility, education for people with disability, but also in further phases extending out to support networks and other members of people with disabilities networks.

Just to talk you through our pilot framework. This is based on a framework that has come out of Stanford University called, Our Voice framework. Now they have a very specific

mechanism, an app they used to collect data. It has been using some health care settings, particularly with people with aging populations. In fact it was used by some researchers out of the University of Queensland within the last three years. Our method is loosely based on that, we are using the different technologies, that I mentioned to collect our data. The important thing I think is, the process that we started with vision. This vision means that the research is grounded in the perspectives of people with disability. From conception to planning stage, we have embedded citizen scientists, Angel being one of them, Dr Kevin Cox AM being another, in all aspects of the research to ensure that any outcomes and solutions, do more than just benefit people with disability or what we think would benefit people with disability, but actually provide meaningful understanding and mechanisms for change. The way we do this is we had some initial steering group discussions that assisted in developing and generating the research agenda and its priorities. Three citizens with disability are on the project team and directly embedded in the day to day research, which is how we continue to embed this vision throughout the project.

Uncover which is our stage two, which we are in at the moment, we're in this uncover stage Using the consultation hub to collect data, we're collecting data about experiences, stories, people's understanding of dignity and of what is undignified. It's important to note, that for this stage, we chose the word uncover, because the data is not being discovered by the research team. We are just giving people a platform and space in which to share things that they have already discovered or experience for themselves. This isn't new information to the people who are participating in the survey, so we are not discovering anything you new, were just uncovering those experiences. And that's a really important value, I think of our project.

The next phase discuss, will see us bring together in our focus groups, I mentioned, our citizen scientists, key stakeholders and researchers. We'll discuss and build consensus around the initial data analysis and data collected through the survey, to start to build a framework of how dignity is understood and experienced by people with disabilities. This stage is also going to involve further engagement with the members in the community hub.

The next stage, the reimagined phase, will use the community hub to build a new understanding of not only the concept of dignity, but obviously of this citizen science pilot that we're undertaking, where researchers and people with lived experience, partner together to undertake research. Through our pilot we hope to produce outcomes and solutions that will reimagine how dignity can be protected and maintained, despite the current physical economic environmental and attitudinal barriers. We also hope that this pilot of citizen science is something that can be carried forward into other projects and other settings.

Finally change, and this is one of the fundamental elements of citizen science research. It's not just about getting to that reimagine phase. it's about pushing beyond that and pursuing an empowering agenda for change, that will translate our results and outcomes into meaningful recommendations, reports and systems for building a more dignified and accessible society for all people. So far, I would say, we're moving through it well. We have definitely had some challenges and some hurdles to overcome, COVID-19 obviously being one of them, but it has forced Angel and I and the rest of the research team, to adapt to these virtual environments and consider what accessibility actually means for our project and beyond that. Were really interested to hear feedback from you, so if you're curious about the framework that we are piloting and how that might apply to you, were really happy

to talk about it and discuss with you. Now I'm going to actually hand over to Angel. Angel is a dignity project research team member and she's going to elaborate more on importance of codesign and the importance of citizen science for people with disability and also what our community hub actually looks and feels like, so sending you live now Angel.

[Onscreen: Angel Dixon, THC Ambassador and Citizen Scientist on The Dignity Project, The Hopkins Centre

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Thanks everyone and thanks Kelsey. You will also have to bear with me a little bit today. This is one of my first virtual presentations, so there might be a bit of awkwardness, but thank you for dialing in. Kelsey and Elizabeth have done a good job articulating exactly what we're trying to do and what citizen science is. Thank you all for your interest in this project and also for being part of such a forward-thinking community, which is The Hopkins Centre. Research is a new adventure for me. I come from a not-for-profit and activism background, and also from my own background of lived experience in a number of ways. Which is actually how I first connected with Elizabeth on LinkedIn, probably a couple of years ago now. As a person with disability, with an interest in rights and philosophy, I usually find it hard to engage in projects like this, particularly in the medical arena, because of what Kelsey has already discussed. I personally feel that there is a general lack of understanding of contemporary values for people with disability and about disability in general. After connecting with Elizabeth and learning about the goals of the project and the values of The Hopkins Center, I was really keen to be involved in this pilot project in any way. As Kelsey and Elizabeth have explained, this project aims to embed lived experience into its research, by bringing people with disability to the research and development table. Which is something that I'm really passionate about. But we're all born into a society with misinformation about what disability is and who people with disability are, which is why I'm so passionate about, hopefully the outcomes at this particular project. The fact is that people with disability are people and what we need are equitable ways to achieve our goals, which is something that everyone needs. For people with disability diverse individuals, who just live in a world that isn't developed with us in mind. So a lot of us have a really fine-tuned lens for the barriers that block our full and affective participation in our daily lives. Which is what makes us keen citizen scientists. There is a phenomenon that I like to 'call exclusion because of confusion' in our society. It is kind of a phrase that I've coined over the last few years and I think because of the nature of impairment, and it's infinite number of ways that people communicate and live their lives, inclusion isn't a black and white concept. Rights however are pretty clear, but in the gray area of inclusion, people get pretty confused and some people often choose to do nothing. In other cases some people choose to do everything. But in both of those cases, there are violations of individual rights in some way. So what the Dignity Project is trying to do, is to marry those together and find a balance, so that we can really define dignity and change. In the past when designing things for people with disability, our experiences, as Kelsey has said, have been overshadowed by the wants and needs of networks, support networks and rigid systems and services, and more often than not, a service or product is actually created in reaction to a problem or a system failure for one person, which then leads to a whole bunch of band aid fixes for many. Those fixes are again more often than not, are made to suit the designer or the funding body, rather than the person or the people that the solution was intended to be created for. Those services and designers are, well meaning. In their haste to fix the problem, they don't necessarily think about the individual human rights of the user and they

don't think to engage people with disability in significant and meaningful ways. As I also mentioned earlier, my background is not in research, so most of the examples that I have in my toolkit aren't specific to research, but I do find that examples about inaccessibility and exclusion are fairly universal, so I have an example when I just wanted to share with you now.

It's actually from an article that's been going around over the last couple of months from the New York Times about the new Long Island library in New York State. It's actually it's an interesting read if you have the time, but I will share a snippet of it with you now. It has been heralded as an architectural triumph, a new 41.5 million dollar library in long island city that ascends over multiple landings and terraces, providing stunning Manhattan views to patrons as they browse books and explore. But several of the terraces at the Hunter Point library are inaccessible to people who can't climb the stairs. The staircase and bleacher seating in the children's section, was judged too risky for small children and has been closed off. The five story vertically designed building only has one elevator. The article then goes on to say that the line for that elevator for parents with prams is ridiculous and that people with disability can't even access the elevator because of line. And that photo is actually a very grumpy children and parents. It then goes on to say, that a senior partner at the firm that designed the library, said too much emphasis was being placed on the inaccessibility of the terraces. Which they called a small wrinkle in an incredibly successful project. I'm just going to let that sink in for a second. Because that final line actually says a lot and as a person with disability, I feel a lot when I hear it. That line, I could say a lot about universal design and attitudes at this point but that's perhaps for another presentation. What I will say is that if that architect had embarked on some inclusive research or engaged people with disability at the beginning of the design process, it wouldn't be costing one their reputation, or the significant additional funds that's required to fix that problem now. Retrofitting research, retrofitting systems, products, services, online and physical environments, anything, really costs loads more time and money, then just engaging people with the lived experience of the problem that you're trying to solve, at that design level. The most dangerous part of those band aids vectors, fixes or retrofits when it comes to people with disability, is the everyday loss of dignity that we experience, when interacting with the world around us. Infringements on dignity, like both Elizabeth and Kelsey have said, come in many shapes and forms, in the example of the library, it is basic exclusion. Which has an impact on personal dignity in a number of ways. But it could be as simple as a sorry look from someone on the street when you going about your daily life, to something like the abuse of a student in a classroom or the neglect of a tenant in a share home. The manifestations are different, but the personal experience seems pretty much the same. In the case of research, because of the varying degrees of inclusion and understanding about disability, people with disability don't always feel comfortable sharing their perspectives or experiences with researchers. I as I mentioned in the beginning, am always hesitant when partnering with an organization or when working with these types of projects. Because of that fine-tuned lens that a lot of us have, we are not sure how information will be used or framed or communicated in reporting or applied in outcomes. But because the Hopkins center understands the value of diverse perspectives in research and innovation, the dignity project team strives to stay up to date with contemporary values and we welcome all perspectives and experiences. Part of ensuring that citizens feel comfortable sharing their experiences in this project, is through ensuring that what we're doing is inclusive by considering language, framing and accessibility across all elements of our project, something that Kelsey's already discussed. One of my roles on this project is as Community Hub Moderator. The Community Hub that we have up now, was launched in

April and anyone who is a person with disability can go and become part of our community. But hub in short, is a way for us to collect the data that we need, to determine what dignity means to people with disability through positive or negative experiences. The way that we are analysing those experiences is by posting fortnightly forum questions for community members to answer. The answers remain on the platform for, even after the forum closes for transparency, community interest and education. But the platform is actually a lot more than that. We actually do have a few other features in there, we have got some blogs and that sort of stuff, but I feel that the platform itself is a place for people with disability to share their perspectives in what I hope is identified as an inclusive and innovative place. The beauty of citizen science is the element of community. Which is why I love that we've called it the Community Hub. Working together as a community to define dignity, is something that I'm incredibly excited about. Now when I say excited, I'm not under any illusion that the stories or the experiences that we received through the hub will be overwhelming positive as Kelsey is already said, unfortunately even through my lived experience, the negative experiences do in a lot of cases outweigh the positive. But I'm excited for what our outcomes may bring and what change we can in act at the end. The future of this project I think is really promising, not only do I have high hopes for the outcomes, but I believe that this that project is the foundation of a body of much broader work in the future. We are currently seeking funding to make the community hub an application and provide more features. We're looking for collaborators with values that align with our project and with the Hopkins center to help build on the work that we're doing at the moment, because as we've said, this is a pilot. This is the first stage and we look forward to building on this work. I really believe that designing research could accelerate inclusion in every area of life. As humans we design everything, and research and development phases are already built into a lot of things that we design, and I hope that by piloting this project, we can begin to develop truly inclusive research models and produce new and practical outcomes for the future together. So that's it for me, I'm going to hand back over to Kelsey to continue chatting about how you can be involved and to wrap up today. Thank you.

[Onscreen: Kelsey Chapman, Researcher, The Hopkins Centre, Griffith University]

Thanks Angel. Thanks for that was excellent. Just a couple of things as Angel said, about possibly partnering with the dignity project and the community hub specifically. We are looking for projects, people and funders who have similar values that directly aligned with us, to partner by either participating in a forum, were we come together to develop some questions to put towards our community hub members, still keeping in mind of course what Angel mentioned that transparent feedback process, and also to develop further research for the future. If you're interested in possibly seeing what the community hub looks like, I do have some screenshots of that, which I can send through, so just feel free to get in touch with me directly with any questions that you may have.

Now we are going to have time have time for some questions and answers, so if you haven't yet put a question into the chat function on the right-hand side, sorry the Q and A function on the right-hand side. We would welcome you to do that now and we will just be putting up a slide for this period, and Elizabeth, Angel and myself will be answering the questions by audio only. If you would to direct a question to one of us specifically, please feel free to do. So just ask Angel and Elizabeth if you want to answer just pop with your microphone or just make yourself unmuted. You can also follow along with the questions in the chat function if you want to see what people have submitted so far.

[Onscreen: PowerPoint slide announcing question and answer time, listing panel members that will be answering questions via audio only as Elizabeth Kendall, THC Executive Director; Kelsey Chapman, Dignity Project Researcher; and Angel Dixon, Dignity Project Researcher]

[Audio: Kelsey Chapman, Researcher, The Hopkins Centre, Griffith University]

Question and Answers:

Question one:

It is essential that dignity be defined from the perspective of the citizens themselves and provide services that meets their needs, you mentioned that the definition will be formulated from the citizen who is disabled from their perspective. Will there be inclusion of culturally and linguistically diverse groups including first people as dignity can be bound within one's culture tradition and values and may not fit a common description of what I'm doing fine means.

Answer:

Kelsey response: So I might just start us off if that's ok with my fellow panel members. This is a great question and it's something we are looking at, we are looking at a number of intersectionality's for people with disability So it's not just about the disability culture, education, gender as you said culturally and linguistically diverse groups. Immigration is also an issue that plays into this, being viewed as a citizen or as someone who is not a citizen of a country, can also impact on how your human rights and dignity are delivered. It's something we're definitely looking at, intersectionality is with different disabilities, economic, background and location. I know that this is particularly important for first peoples and some cultures where your dignity is tied directly to community and religion, caring for your elder, and so it is something we're examining. I would say it's not the primary aim of this pilot, although we will be looking into it, but it is certainly something we are looking to pursue and some of our future research and my PhD specifically, which is in a little bit of a different vein does examine some of those intersectionality's.

Angel response: I would probably just say that the beauty of the community hub as well is that we are sending this out into social media land and into a lot of other networks. Anyone who identifies from any identity or group can become a member of the community hub and we actually hope and encourage people from as many diverse backgrounds as possible because we need diverse perspectives to come and share their stories and not just share the specifics around what they feel we want around what dignity is or what their experiences have been, whether they're positive or negative. But also share some of those cultural perspectives and some of those individual barriers that they feel they experience, so that we can bring that into the data that we collect now outcomes.

Elizabeth response: Another issue that we discussed at length is how we make the platform really accessible in a range of different ways for different cultures and that might evolve into very different platforms in future, so that sort of information we're looking for as well.

Question two:

I'm interested in hearing about the response from consumers to the Hub.

Answer:

Kelsey response: We are approaching close to 40 members of the Community Hub now. We have been live I think for about 3 weeks, that might be 3 weeks today actually. So far the response has been really positive. You know we acknowledge that there are some accessibility limitations of a SharePoint platform, which is what we have built, but we're doing our best to overcome whatever limitations there maybe. So far we haven't had any complaints and It's been really positive experience. We're just looking forward to really getting into the nitty gritty of it and interacting more on a regular basis with our consumers.

Question three:

How can people join the Community Hub?

Answer:

Kelsey response: We actually have that on our last slide. There's little link that people can click on you can also visit The Hopkins Center website. We have a Dignity Project page you can click on the community hub button and it will take you there. There is an intake form, it's just a quick couple of questions that asks for your email and what disability you identify with if you do at all, and from there we just approve your access. So it's a fairly streamlined process.

The Dignity Project website: <http://www.hopkinscentre.edu.au/the-dignity-project>

[Join the Community Hub](#)

[Complete the Dignity Project Survey](#)

Question four:

How did the dignity project find citizen scientists to partner in the research?

Answer:

Elizabeth response: We are really fortunate in The Hopkins Center that we've always had an orientation about building research capacity in people who are most affected by our research, so we already had quite a process underway with our ambassadors council and those that you've had some interactions with the ambassadors council would know that those people have lived experience of disability and developing research skills and talents in order to promote research as a reasonable activity for all people with disabilities, too many people with disabilities to engage in future. So finding people with disability who had research interests was not that hard at all. But I think one of the most important things to think about was that citizen science is very closely aligned to advocacy and community activism, so it was also really important to find people who have that passion to bring about change in society. So that's how I connected with Angel and I think that was probably the most important move that we made, was connecting with Angel, who is not as she says, not a researcher, she actually has a very scientific way of thinking about things and is developing that even more. But I think more importantly, she had that sense of activism and the drive about using knowledge in a way that makes change in society. I think that's what we were looking for most of all.

Kelsey response: I think for people who are interested in finding a citizen scientist to partner with, the community hub is a great place for you to start. So if you have a particular project that you would like us to connect you with someone who might be interested in working with you on research, just again please get in touch with us and that's something we are hoping

to build capacity for moving forward, were we will have our hope is a project directory within the community hub where individual research projects can make a listing and engage with citizen scientists that way. So that's something we are looking to build on in the future.

Question five:

How will the dignity project report its data?

Answer:

Kelsey response: Reporting is important. At the moment we are funded by the Office for the Queensland Chief Scientist, so we will be doing our reporting to them. We will also be reporting back to community hub members through that platform and ultimately our hope is to develop a report that we can circulate more broadly.

Question six:

Is the dignity project inclusive of children with disability and their families viewpoints?

Answer:

Angel response: It certainly is, the reason that the platform for now or maybe for a while, there maybe another section or in a later stage of research where we have support networks, but the reason that we have personal lived experience and people with disability or people who identifies people with disability or qualify for services, is because we want that that unique lived experience from a personal perspective, that doesn't preclude parents or support workers from assisting a person who requires the support, to participate in the hub from being involved in answering our forum questions and being involved in the hub. So certainly, if there is a kid out there who was really interested in sharing their experiences, we want that, if mom and dad are their support to get them there to answering those questions, come along and do it, totally.

Elizabeth response: It is really important that we evolve overtime. So I think someone's also made the point in the questions, that it's important to hear from citizen scientists who don't have research and activism backgrounds, and that's exactly right. One of the roles that Angel is taking, is to bring other consumers into this system and provide the skills to become citizen scientists themselves. Now that might mean actually asking different questions to what we're currently driving, so we currently driving a couple of questions about dignity and in certain contexts, but as this progresses, there will be opportunities for citizens themselves who are engaging with the platform to be asking you questions and driving new research projects that perhaps don't even involve us. So I think so there's a couple of things there, one is that the platform can be used in future to answer very specific questions for a very specific audiences and in that way our members will be contributing to change in that area and ensuring that that area has good information on which to base decisions. But it will also become a place where we can start exploring our own questions of importance and then feeding that to the right places as we progress. Another point that I just wanted to add, is that it's we have an orientation that people who are doing this research are not unpaid labor for anyone. So while we value the concept of citizen science and that people can participate in science, it's not about being free labor. I think in the disability world, we've had such a long tradition of people sitting on panels and avoid you know contributing to major decisions and not being paid for that when everyone else on the committee is. So we also are committed to looking at ways of making this a sustainable action for the future.

Question seven:

Why is accessible communication so important?

Answer:

Angel response:

It's a great question. It's a loaded question, because there's a lot of things included in what accessible communication is, both from how you communicate things, how we provide our reporting and outcomes, whether that's in easy English and all those kinds of things for people that require it, or as simple as accessibility on a platform, it can extend to inclusive framing and the language that we use when we're discussing disability and making sure that those things are up to date with contemporary values and concepts. But it can also be on the flip side, so it is how a person with lived experience wants to consume. There's just a lot of things in that question. But the importance of all of those things, is that we are making sure that everyone can participate and feel comfortable participating, that's the important thing, because there are a lot of people with disability who just push through, because it's almost close enough is good enough, with the things that we have at the moment. For us, close enough isn't good enough on this project. People with disability need to feel comfortable in sharing their stories with us, so that we can collect the best data and so that we can make better solutions at the end of this, solutions that aren't retrofits, that aren't being built on problematic systems that we have had in the past, they are new and innovative things that come from the wants and needs of people right now. So that's the real importance of it. I am happy to catch up and talk more about the concept.

Question eight:

Will there be coaching for citizens to become researchers within the research team?

Answer:

Kelsey response: Yes, so far that has been one of our priorities as part of our grant. That is, Angel is doing some training. Now obviously due to the COVID19 pandemic, some of our initial plans have changed a little bit around that, but I know that this week she did a systematic literature review course and there's as a couple of other ones that her and I are doing together. Longer term, we do work with Health Consumers Queensland and they have allowed us to put up a number of their consumer engagement resources in our resource library section. So those are available to people to peruse at their own discretion and we're hoping to develop more of those resources, as we go on in order to give people access to more capacity building and training.

Question nine:

Can you share the process for designing the community hub to promote an accessible platform, particular interest for participants with cognitive and communication disabilities?

Answer:

Kelsey response: It's been quite a process. We've been working on this platform since August. We have partnered with the business enablement team at Griffith, particularly a fellow named Marcus, who has been very helpful to us in designing the SharePoint. I think, like we said, there are some limitations in SharePoint, that we cannot address all matters of accessible communication and accessible participation, but at the moment we have done the best that we can. We did have the SharePoint platform tested by Scott Holier who is from the Center of Accessibility, and you know there was mixed reviews on the platform and there are limitations that we acknowledge, due to the Microsoft platform. I think long

term, our plan is to overcome those issues. Again as this is just a pilot, we were just sort of seeing what we could get done. There is a screen reader functionality within the platform itself and it is compatible with the vast majority of assistive technologies as far as we have been informed and as far as Scott's undertaken. But it is an ongoing iterative process for us, absolutely.

Angel response: I think the challenge of this being a pilot, is that unfortunately we are working with the systems that haven't quite been changed yet. So we yeah, we will be working to innovate on our platform moving forward. As far as people with intellectual impairment and people that require different styles of communication, we certainly have access to those things for people who require them. Within the hub if you make it known that you require a different form of communication or a different form of document, let us know, and that's something that we have access to, and we can provide.

Question ten: What are your recommended processes around consumers who want to remain anonymous due to service vulnerability but have lived experiences of abuse and mistrust and want to voice.

Answer:

Kelsey response: Just an initial comment around that, one of the great things about the community hub in this instance, you do need your email to register, but beyond that your participation is anonymous, so all of our forums and all of your interaction within the platform, can be done in an anonymous way. So that is a great place to start. We recognize again, it is just a starting place, but we're building through some functionality around commenting and posting in other ways besides just the forum where you can remain anonymous.

Elizabeth response: Only to add, that it is such an important point, that we need to be able to provide that privacy as well as publicity. Some people want extreme publicity as well and that's something that we should be able to adapt to. But those are the voices, the very voices, that you're talking about, are the ones that need to be collected and shared. I do hope that we get those voices as well and you know if there are things that people think we can do to encourage people who wouldn't otherwise speak to share this story that would be really good advice for us.

Kelsey response: I think in some of the data that we have already seen come through the survey, some of those experiences of abuse and mistrust have already been shared and that is obviously an anonymous survey. People can attribute their name and contact details if they want, but they also don't have too. So far we have had some stories come me through around those experiences and we are hoping that people feel safe to continue sharing with us in that way.

[End of Questions and Answers]

[Onscreen: PowerPoint about Have your say with The Dignity Project, providing details and links to complete the dignity project survey, join the community hub and contact the research team]

[Audio: Kelsey Chapman, Researcher, The Hopkins Centre, Griffith University]

That's all we have for today. I'm just going to put up our last slide about how you can connect with us beyond this meeting today. We really appreciate all of you making the time to join in us for this Hopkins Hour and 9 minutes. It's been such a pleasure to have you all, although very strange not being able to see any of you. We will distribute the video recording and a short survey along with any other questions that come in next couple of minutes, to all of the subscribers and people who have joined us today. Thank you so much for your interest. Hope you have a lovely week.

To learn more about The Dignity Project and to have your say in the Community Hub and research survey, please click on the links below or visit our

website: <http://www.hopkinscentre.edu.au/the-dignity-project>

[Join the Community Hub](#)

[Complete the Dignity Project Survey](#)

Click [HERE](#) to contact The Dignity Project Research team or email The Hopkins Centre at hopkinscentre@griffith.edu.au

[End of Hopkins Hour]

