**Raw Transcript**

Centre of Research Excellence

in Disability and Health Webinar - How can we use quantitative data for disability research?

(Via Microsoft Teams)

Wednesday, 24 August 2022 at 10am

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PROF. DENNIS PETRIE: Welcome, everyone. We'll just wait for people to join the meeting.

We're just waiting for everyone to join the meeting. We'll get started soon.

Great. Well, I think nearly everyone is in, so we'll get started. Thanks so much for coming. Today we've got an exciting session ahead. So first, I'm Professor Dennis Petrie. I'm based at the Centre for Health Economics at the Monash Business School at Monash University.

So today I'd like to welcome everyone here today and I'd like to ‑ I wish to acknowledge the traditional owners of the land which both the speakers are on today and all of you sit on today and, in particular, I'd like to acknowledge the traditional owners of the land that I'm on, the people of the Kulin Nation, and I pay my respects to their Elders past, present and emerging.

So I just want to give a brief introduction for the Centre of Research Excellence in Disability and Health. So I suppose all of us today are part of this group and it's funded by the National Health and Medical Research Council and so the idea of the Centre of Research Excellence in Disability and Health is to improve the health of people with disabilities with a particular focus on examining the social determinants of health for people with disability and so in order to do that, a key part of that is to develop the evidence base in order to guide health and social policy to improve the health of people with disability and so lots of the work that we're going to see today is kind of this journey that we've been on for the last five or six years exploring what data is actually out there in Australia, what it means and how we can best use it to help inform policy. So that's what we'll do today.

So a few housekeeping things to start with. I'd just like to note that the session is being recorded so it can be shared later. If for some reason you don't want to have your questions or things recorded, please contact us through the email and let us know. If you have any technical problems during the session, if it is put in the chat and someone will pick it up and assist you. The other things to note ‑ the URL for the live captioning is provided via Captioning Studio and it's been pasted in the chat and so this should open in your internet browser, so if you look in the chat there if you need that.

So during the talk we won't have questions, but there will be a Q&A session at the end, so what we'd like you to do is during each of the presentations actually is just to put your questions into the chat box and we'll pick them up at the end in the Q&A, but while they're kind of fresh in your mind, make sure you write them down and we'll come back to them later.

So I'd like to kick off by introducing our four speakers today and so I suppose we've got our first speaker, Dr Nicola Fortune, we've got Dr Zoe Aitken, we've got Dr George Disney, and Dr Samia Badji. They're our four speakers today, but first I'll hand over to Dr Nicola Fortune, who is going to be talking about measuring inequalities using survey data. Thanks, Nicola.

DR NICOLA FORTUNE: Thanks very much, Dennis, and thank you everyone for coming along to the webinar today. I'm Nicola, I've been working as a research fellow with the CRE over the past four years based at the University of Sydney and in this presentation, I'll talk about using national survey data to measure inequalities in social determinants of health between people with and without disability.

So I'll start by talking about why we might want to measure inequalities and I'll introduce the Disability and Wellbeing Monitoring Framework. Then I'll talk about how we've used survey data to measure inequalities between people with and without disability and I'll take a little time to talk about how people with disability are identified in national surveys conducted by the Australian Bureau of Statistics. Then I'll finish by highlighting some data gaps and limitations.

So why measure inequalities? Well, here are a few reasons. First, Australia ratified the Convention on the Rights of Persons with Disabilities in 2008, so we're obliged under international law to implement the Convention and implementing the CRPD means taking action to eliminate inequalities so that people with disability can enjoy all human rights and fundamental freedoms on an equal basis with others and of course social determinants of health are modifiable, so as a society we can take action to reduce and eliminate inequalities.

Second measuring and reporting on inequalities can help raise awareness and be a spur to action; third, measuring inequalities can identify priorities for policy action and for more in‑depth research to inform that action; fourth, monitoring inequalities can help to evaluate the effects of policies and interventions and using data to evaluate and model the effect of policy interventions is something that will be picked up in some of the other presentations in this webinar; and finally, measuring and reporting on inequalities can help to hold key actors to account on commitments made to improving outcomes and reducing inequalities experienced by people with disability.

I'm just trying to get my slide to change. There we go. So it was a key aim for the CRE right from the outset to develop a monitoring framework and indicators to measure and track inequalities between people with and without disability. We developed the Disability and Wellbeing Monitoring Framework drawing on several existing frameworks and indicator sets and with input from an expert panel of advice comprising 14 people with disability and three close family members of a person with disability.

This slide shows the structure of the monitoring framework, so it has 19 domains grouped under these three broad headings which are health, social determinants of health, and service system, and it has 127 indicators.

In June this year we released the baseline data report and the intention is that this will provide a baseline for monitoring change over time across the 19 domains of the framework. You can access the report on the CRE website or by scanning the code that's on the screen there.

Okay, so who are people with disability and on the flipside, who are people without disability? If you're measuring inequalities, you need to give some thought to how you define the two groups being compared. Now, many of you will be familiar with the World Health Organization's International Classification of Functioning, Disability and Health. This slide shows the ICF model of disability. The ICF is an internationally standard framework and over the past two decades it's informed the way that disability‑related data are collected and analysed in Australia. The ICF conceptualises disability and functioning in terms of the dynamic interaction between a person's health condition and environmental factors and personal factors and disability is an umbrella term for impairments, activity limitations, and participation restrictions.

Now, the ICF emphasises that functioning and disability exist on a continuum, so to measure inequalities, we need an operational definition of disability that effectively places a cut point somewhere on the continuum of functioning so we can identify people with and without disability.

Australia's national disability survey is the Survey of Disability, Ageing and Carers, or SDAC for short, and it's a very important and rich data source. It's been conducted every three years or so since 1981 by the Australian Bureau of Statistics and the definition of disability used in SDAC is "Any limitation, restriction or impairment which restrictions everyday activities and has lasted, or is likely to last, for at least 6 months". This definition is operationalised in the survey using a lot of questions about health conditions, impairments, activity limitations and participation restrictions and this operational definition is the basis for Australia's national estimates of disability prevalence.

Now, ABS also has a short disability module which is designed to be consistent with the SDAC approach for identifying disability, but it uses fewer questions, and that short module is used in a range of other surveys, including the National Health Survey, Survey of Income and Housing, the General Social Survey, and the Personal Safety Survey. And both SDAC and the Short Disability Module also enable identification of people with severe or profound core activity limitation, so that's people who sometimes or always need help with self‑care, mobility or communication activities, and having this consistent approach to identifying people with disability and also the sub group of people with more severe disability means that we were able to draw on multiple different surveys to report baseline data for the disability and wellbeing monitoring framework across all 19 domains and the next few slides give some examples of the data in the baseline report.

So the baseline report really shows quite starkly that Australians with disability experience inequality across all areas of life. So, for example, for people aged 18 to 64 only half of people with disability had a job compared with 81% for people without disability. In the housing domain, 48% of people with disability were home owners, compared with 61% of people without disability. And in education, 46% of people with disability had completed high school, compared with 64% of people without disability. Now, these are really big gaps and the data illustrate or demonstrate the need for really concerted action to reduce these inequalities.

The graphs on this slide are for the same three indicators, but they show results for people with severe disability ‑ that's the green bar in the middle ‑ and this is the group of people who sometimes or always need help with mobility, communication or self‑care and the data show even greater inequalities for this group of people. So, for example, only a quarter of people with severe disability had a job compared with 81% of people without disability; 39% of people with severe disability were home owners, compared with 61% for people without disability.

Now, of course people with disability are not by any means a homogenous population group and high‑level data like these can't capture the diversity of experience and outcomes, but by disaggregating the data ‑ for example, by age or gender ‑ we can start to get some important insights into how outcomes and inequalities vary across different sub groups of the population of people with disability. So this slide shows data for median weekly disposable income and for this indicator we presented data separately for three age groups, so people aged 15 to 24, then 25 to 49, and 50 to 64, and the graph shows that people with disability had lower incomes than non‑disabled people in every age group, but inequalities increased with age, peaking in the age group 50 to 64 years, and so people in that age group had a median weekly disposable income of $526 compared with $909 for people without disability.

The graphs on this slide show personal income was generally lower for women than for men, but income inequality for people with and without disability was greater for men than for women. So, for example, women with disability aged 25 to 49 years earned $152 a week less than women without disability in that age group. For men aged 25 to 49 the gap was bigger, so men with disability earned $318 a week less than men without disability.

Now, in this final part of the presentation I'll just talk quickly about some data gaps and limitations. So the monitoring framework has 127 indicators. We reported data for 93 of those indicators, but for 34 indicators ‑ that's about a quarter of all the indicators in the framework ‑ disability disaggregated data were not available. So, for example, we couldn't report data for incidence of specific cancers, prevalence of poor dental health, experiencing bullying or harassment, or feeling safe on public transport, and it's important to make the point here that most national administrative data sets lack a disability identifier, so, for example, in the national hospital data collection it's not possible to identify patients with disability and where we don't have data disaggregated by disability status we can't measure or monitor inequalities.

Data linkage is potentially a way of using disability identifiers available in one data set to analyse data by disability status across a range of linked data sets and there have been great advances in data linkage in Australia over recent years and currently there's work under way to produce a National Disability Data Asset. Ideally, such a linked data asset would include a disability identifier that's consistent with the operational definition of disability in SDAC and not limited to identifying people with disability solely on the basis of contact with disability‑specific services or programs or payments like NDIS or the Disability Support Pension.

Final point I want to make is that key groups of people with disability may be missing from or underrepresented in data sources. So, for example, many ABS surveys don't cover people living in very remote areas or discrete Aboriginal and Torres Strait Islander communities or in non‑private dwellings, which include places like boarding houses, prisons, hospitals, nursing homes, and disability group homes. Also, people who can't answer survey questions for themselves might be inadequately represented, so either a proxy person might be interviewed on their behalf or they might not be able to participate in the survey at all. And this is really another aspect of the question who are people with disability in the context of a given data source and whatever data source you're using, it's important to think about who's captured and who isn't and the implications for interpreting the data.

Just a quick recap of key points. So having a consistent approach for identifying disability across different data sources is really valuable. The consistent operational definition of disability across ABS data sources meant we could draw on data from different ABS surveys to report on inequalities across the full range of social determinants of health, but there are still lots of data gaps. We couldn't report on about a quarter of the indicators in the framework because disability disaggregated data are not currently available. Many of these gaps could potentially be filled by administrative data if a disability identifier was present.

And finally, I'll emphasise again the importance of understanding who are people with disability in the context of a given data source and thinking about the implications of the operational definition of disability used and which groups of people with disability might be inadequately represented. And this point will be further illustrated in the following presentations in this webinar. You'll hear about analyses conducted using different national data sources and the operational definitions of disability used in those analyses.

So that's it from me. Thank you again and I'd like to hand over now to my colleague Dr Zoe Aitken.

PROF. DENNIS PETRIE: Great, thanks, Nicola. If you have chat ‑ if you have questions, make sure you put them in the chat. So I suppose Nicola has pointed out just how important it is to monitor health inequities for people with disability. So I suppose to do that we need good data and we've got some good data that we should definitely utilise that's there currently, but there's definitely improvements we need to make to our data that is available to better understand where those problems may lie and also for some groups not represented in the data so far. Great, thanks, Nicola. So now we're going to move on to Dr Zoe Aitken, who is at the University of Melbourne. So she's going to talk to us how do social determinants contribute to mental health inequalities? An analysis using longitudinal data. Thanks, Zoe.

DR ZOE AITKEN: Thanks, Dennis, and thanks, Nicola, for such a great start to this webinar. My name is Zoe Aitken, I'm a Senior Research Fellow at the University of Melbourne and I've been working as a postdoc on the CRE since it started in 2016. I'm an epidemiologist and my main research interest is in understanding mental health inequalities and generating evidence to drive change to improve mental health for people with disability.

In this presentation I'm going to talk about the potential of longitudinal data for disability research and highlight its strengths and limitations; then I'm going to use an example from my research demonstrating how you can use data from a longitudinal survey not designed to look at people with disability to answer causal questions about the social determinants of health for people with disability.

So to start with, well, let's think about what are longitudinal studies. Now, the key feature of longitudinal studies is that they follow the same cohort of people over time who answer surveys or questionnaires at different time points to start to weave a picture of how their lives are changing over time. As an epidemiologist, I'm interested in estimating causal effects. I want to know how a change in an exposure ‑ and that could be a change in someone's personal circumstances such as change in someone's employment status, but it could also be a policy change or COVID lockdown ‑ I want to know how does that change in circumstances cause or lead to changes in that person's health and that is evidence that advances our understanding of the determinants of population health.

But estimating causal effects is challenging and this series of presentations aims to describe how we have approached this challenge in the CRE to generate the best possible evidence about the social determinants of health for people with disability and this is evidence that we think is policy relevant because it provides a better understanding of the causal determinants of health outcomes and therefore evidence highlighting potential policy targets to improve health outcomes and close current inequalities.

So on to some strengths of longitudinal data. Longitudinal data and longitudinal surveys are designed for research purposes. The data are collected for research purposes, so the data are easy to use, to answer research questions.

Now, as I mentioned already, the study design of longitudinal surveys follows people over time and that means we can start to examine causal questions to understand whether changes in the social determinants of health lead to changes in health outcomes. Longitudinal surveys collect data on a large number of variables, a large number of different life domains using a very detailed questionnaire, so there's scope to examine a large number of different determinants of health and a large number of different health outcomes that may not be available in administrative data sources and these are variables such as, for example, self‑reported health and wellbeing outcomes.

Longitudinal surveys are often designed to be representative of the whole population or can be analysed in a way to make them representative of the whole population. And finally, the data are provided to researchers or data users in de‑identified formats, so anonymised data. Now, longitudinal data sources can be used to generate high‑quality evidence about the social determinants of health for Australians with disability.

Now, on to some weaknesses. There are also some limitations that need to be understood when we use longitudinal data. These data sources mostly are not designed for disability research. They might not be representative of the population of people with disability in Australia, so, for example, some sub groups may be less likely to be represented and as highlighted by Nicola in her presentation, such as people with disability living in supported accommodation.

Related to this again there may be small numbers of people with disability and this might be particularly true when we start to look at sub groups of people with disability. For example, there may be few young people with disability in the sample, or we might have problems with small numbers when we start to disaggregate the data and look at different disability groups.

Again, related to Nicola's presentation, the definitions of disability used in different longitudinal surveys vary, so the definitions of disability and the way disability information is collected will vary and we need to think very carefully about what population of people with disability is represented in our sample. The group of people with disability identified in longitudinal surveys may not be comparable with SDAC, the Survey of Disability, Ageing and Carers, or other ABS data sources.

And finally, when a cohort of people is followed up over time, there is always loss to follow‑up. People cannot be traced for a variety of different reasons, so that means that our sample will become smaller over time and may be less representative of the target population.

So, so far in this presentation I have highlighted the key features of longitudinal studies and their strengths and weaknesses for disability research and now I'm going to talk about the types of policy questions that can be answered using some examples from our research and then I'm going to expand on one of these examples.

So these are just a few examples of the types of policy questions that can be answered. So it's possible to use longitudinal data to examine the effect of policy changes ‑ for example, we could ask the question what is the impact of the NDIS on the mental health of people with disability? We have information on people's mental health before and after the implementation of the NDIS and so we can use this information to isolate the effect of the NDIS on mental health.

We can also use longitudinal data to examine the effect of transitions. So we could look at the impact of gaining employment on mental health for people with disability. Again, we have information before and after changes to people's employment status and so we can isolate the impact of employment on people's mental health.

And finally, we can also use longitudinal data to explore pathways or mechanisms by which effects operate. So we can ask the question why do people with disability have poorer mental health than people without disability? And we could investigate how the social determinants of health contribute to the effect of disability acquisition on mental health, and this is the example I will be talking about in more detail focusing on the contribution of employment. So this is examining the causal processes driving mental health inequalities.

So the research I'm going to be talking about is part of a large body of work that we have done demonstrating the beneficial effects of employment for the mental health of people with disability. A key finding is that while employment is beneficial to mental health in the whole population, what we find consistently is that the mental health benefits associated with employment are greater for people with disability compared to people without disability. So this really highlights that employment is a key determinant of mental health for people with disability.

In this piece of research we are interested in asking the question why is disability acquisition associated with a decline in mental health and how much of the effect operates through changes to people's employment. There are likely to be multiple complex pathways leading to a decline in mental health for people who acquire a disability with lots of factors operating simultaneously. The longitudinal data allow us to separate out the effect operating through those different pathways or mechanisms and we call this a mediation analysis. In this example, which is illustrated in this very simple causal diagram, we were interested in isolating the effect operating through employment to understand how much of the decline in mental health is occurring through changes to people's employment.

For this analysis, I used data from the Household, Income and Labour Dynamics in Australia survey, HILDA. HILDA collects yearly data from the same cohort of people who have been followed up every year since 2001. For this analysis, we used data from four years of the survey from 2011 to 2014 and we restricted our sample to the working aged population.

The disability question in HILDA asked people if they have a long‑term health condition, impairment or disability that restricts everyday activities, and has lasted for 6 months or more. It identifies people with disabilities and health condition and as such, it's a broader definition than the group of people who might be identified in ABS surveys such as SDAC.

And we defined the exposure as a disability transition. We identified a group of people who acquired a disability in working age and then looked at subsequent changes to their employment and mental health.

On to some results. Our study estimated that on average people who acquired a disability had mental health scores that were five points lower than people without disability. A five‑point difference in mental health scores is thought to be a clinically important difference in mental health. So we found large differences in mental health between people with and without disability.

When we conducted the mediation analysis, we estimated that 11% of the effect was operating through changes to people's employment. For people who acquire a disability in adulthood, 11% of the decline in mental health was attributed to changes to their employment status, so becoming unemployed. So this evidence further suggests that being employed is an important contributor to mental health inequalities and reinforces that it's an important target for policy interventions to improve the mental health of people with disability. But we also know from our other work that it's not just being employed that has mental health benefits. It's being in meaningful, sustainable employment. So the total effect of employment is likely to be considerably larger when we take into account the characteristics of people's employment and this is something we are examining in current work that we are doing at the moment.

So I hope in this presentation I was able to convince you that longitudinal surveys are a very valuable data source for disability research and that I provided some insights into what using longitudinal data can do in generating high‑quality evidence that we can use to take action on current health inequalities. I want to leave you with a reminder of some key messages. Longitudinal data can be used to estimate causal effects by examining the impact of transitions or policy changes. It can be used to examine mechanisms and to understand the relative importance of different pathways and this is important for identifying the key social determinants of health implicated in these pathways to know where to target policies to improve health outcomes. And finally, another important point that I'd like to remind you is that the data are easy to access and they are easy to use for research purposes.

But as with any data source, it's important to understand the limitations of the data and the population of people with disability that are represented by the data.

And finally, to finish, I would like to acknowledge the lived experience that contributed to these data and also highlight the value of complementing epidemiological research with qualitative research to understand the in‑depth experiences of people with disability and interpret the findings within the context of the lived experience of disability. Thank you.

PROF. DENNIS PETRIE: Great. Thanks so much, Zoe. So yes, so Zoe has kind of emphasised the point of we might monitor the inequities for people with and without disabilities but to kind of know what we have to do on the social determinants of health to improve the health outcomes for people with disabilities then we kind of have to move our analysis into more causal analysis to try to understand what works and changing what exactly, for example, employment, you know, how much will that impact on our health outcomes. So that's great work. Thanks so much, Zoe.

We might move on to our next speaker. I'll just get the slide, excellent. So our next speaker is Dr Samia Badji and so she's going to be talking about what are the unintended consequences of policy reform, the 2014 Disability Support Pension reform. I just remind people to keep putting your questions in the chat. Thanks so much for those who have already asked questions. Thanks. Over to you, Samia.

DR SAMIA BADJI: Thanks for the introduction. Thanks to the previous presenters, Zoe and Nicola. I'm a health economist at CHE. I use quantitative data to improve health outcomes of disadvantaged and vulnerable populations, in particular people with disability. I'm very happy to present on the unintended consequences of policy reform, so we're going to look at a policy which aimed to encourage work but led to increased dispensed medication that includes antidepressants. This is joint work with Anne and Dennis.

So the number of DSP recipients has been increasing over time. This is true in Australia and elsewhere. There's been policies to restrict applicants and some have reviewed DSP recipients and so we're looking at one that's reviewed those who were already receiving the Disability Support Pensions against this new impairment tables and so the aim was to move people off welfare into work and there's a large majority of evidence in reports or in academic publications, but it's mainly focused on employment and so we wanted to ask what's happening to health or at least healthcare use. Work may be good for your health, but we're looking at a more vulnerable population that we're trying to push into work, so this is why we're interested in this question.

So the data I'm going to use are this great data, MADIP data, linked data from several government entities and that includes welfare benefits through the DOMINO database and health care use. It has other information on census, traineeship, apprenticeship, tax returns and so on, so this basic longitudinal covers years 2011 to 2016 and our reform is in 2014, so it's fairly easy to use. The main strength of this kind of data set is that you have almost everybody ‑ for example, investigating this policy reform which looked at those under 35 and on DSP, which would be very challenging with HILDA because you would run into low numbers very quickly. The other strength is that it's a longitudinal data set and this data set is regularly expanded and updated with new years.

Now, one of the weaknesses is that of course being on DSP is different from having a disability. There is severe indicator for disability in the census that can be used. If you want to know more about how disability and being on DSP and how they overlap, we were involved in an NDDA test case that Zoe led and hopefully this will be available soon.

The newest data do have information on SDAC as well, so a survey looking at people with disability, and so you can actually use that definition if you want to understand how those on DSP and those who would be defined as having a disability with SDAC, how it's overlapping.

For the purpose of our reform, we're very happy to have people who are on DSP so we can look at the impact of those that were reviewed and their health care use.

So the strategy, because the reform only was implemented in 2014 and because we have this great longitudinal data set, we can look at people before and after the reform and so we can investigate their use of antidepressants through one item which is the number of dispensed medication for the nervous system. Now, of course even if I look at these people before and after and Zoe did a great job at explaining causal identification, many other things may have happened in that time frame and I do not want to say that everything comes from the reform, so I want to look at another group and compare this group that was affected with the group that wasn't affected and this is arguably the best thing you can do in terms of causal identification is to look at your group that is treated and compare it with one that wasn't and so because the reform only looked at those under 35, we're going to look at those who were over 35 and on DSP.

Now, given the wealth of data set with MADIP, we could have chosen to look at those not on DSP and under 35 or many other groups. We have chosen these people because they look pretty similar up until 2014, as I will show.

Now, given the data challenges to look at few people in data sets, the first thing you want to do is probably check that you can actually see the reform in your data and so this is what we're going to do in the next graph. So this graph shows the number of ‑ the rate of DSP exits for different age groups, so the vertical axis is DSP exit rates and the horizontal axis is time and so I've plotted different curves for different age groups, so we have those aged 31 in 2014, then another line for those aged 32 in 2014, and so on. And so what you can see is that most of these age groups did not ‑ there's no particular trend emerging before 2014, it's fairly flat, and then a few of those lines are jumping after 2014 and these are people aged 34, 33, 32 and 31 years old and the other curves are for those 35‑year‑olds and they still remain flat, so we can see that the reform did happen.

Now can we see stress? So we can't really see stress, but we can see an extreme measure of stress which is the use of ‑ the dispensed medication for nervous system. And so this is what this graph plots. On the vertical axis you have dispensed medication for nervous system and on the horizontal axis you have time from 2011 to 2016, those under 35 years old targeted by the reform and those who are under 35 years old who are not targeted by the reform. To see better how the two groups are doing before 2014, I have artificially put the number of scripts at 0 for 2011, so effectively looking at how scripts have evolved with respect to 2011. So we can see that before the reform these two groups behaved very similarly, so I can use them as a comparison ‑ I can use the control group to compare the effect of the reform with those treated and after the reform I can see a split and those who are targeted by the reform have higher dispensed medication for the nervous system. So this would point to stress.

Now, this is a very large data set. If you look at many outcomes, you could see that randomly some things are going up. So we wanted to know if this makes sense with respect to the data. So how can the nervous system scripts or dispensed medication increase over time? So of course you need to see your GP or your specialist. So these two graphs show the number of GP visits on the left and specialist visits on the right, so it's the same as the one I've shown before, I've put 2011 as a reference group and we just see what's happening with the number of visits for these two groups.

So we can see again that after the reform those who were targeted by the reform have higher use of GP visits and specialist visits. You can see that this is happening already a little bit in 2014 and one reason for that is that to remain on the reform you had to provide current evidence if you were under review that you still meet the criteria to remain on DSP and this is why the reform artificially led to people seeing their GP or specialist to gather evidence.

Now, if you're kind of forced to see your GP or specialist sooner than maybe you would have wanted to, that could lead to early detection of medical issues. So this might just be something happening with the nervous system script. So if so, we would expect to see that everywhere. So these are three graphs showing scripts for dermatology, sex hormones and musculoskeletal system and for dermatology and genitourinary, sex hormone scripts, you can see there's no big change after the reform. Maybe for musculoskeletal you could see slightly something but that would only be 2016 and as I will show in the next slide it's not statistically significant.

So this slide summarises this graph. We can see the effect of the reform and we can see that for different outcomes. So if we stick to the four columns on the right, it's all about dispensed medication for different types and we can see that only nervous system scripts is statistically significant, so three stars at one person, and we can see there's also an increase in GP and specialist visits. So in the end the reform 0.2194, 0.2 more scripts for the nervous system, this is per person per year. That's about 12,000 additional nervous system scripts. It likely increased stress given that we do not find such effect for all the scripts. And this has led to about $2.2 million in extra health care costs. It's not the biggest, but this is a huge underestimation.

For technical reasons, I had to have my two groups to be similar and I have focused on those 29 to 32 years old. This is obviously a subgroup of all the people who are under 35. Also these costs exclude costs to the judicial system and we know there were many appeals to remain on DSP and of course it's also excluding costs to the carers and also the cost of the reform.

So in the end it would be great if future policies could try to account for these potential unintended consequences, now that they are knowing that it can lead to significant stress. That would be my key message.

To come back to the data, there's so many questions that you could investigate with MADIP. Currently we are looking at the long‑term consequences of the policy reform because after 2016 that was not available when we did this work. You have survey data, so SDAC and also the national health survey. There is information, so there's really a lot of information available with MADIP. I just give an example about how public transportation affects health care use, because this is work I was involved in and there is no information on public transport. So it's just to say that there is this wealth of data available with MADIP but if you're interested in a certain policy questions, you can easily vet in data, not individual data, that would be another story, about you if you have data at location level, it's very easy to vet them in so you can look at other aspects as well. That will be it for me. Thank you very much and if you have any questions or comments, you can reach out in the chat and we're all happy to answer questions down the line as well and if it helps in your work to look at this presentation, I'd very happily hear from you. Thank you.

PROF. DENNIS PETRIE: Great, thanks, Samia. I suppose Samia has kind of highlighted how we can look at policy changes in Australia and we can use the administrative data that the ABS and others have given us access to to look at what the implications of different policies were and so again, it's kind of how we might use the data that is available to kind of better understand the consequences of different policies that might have been interacted and so it helps us adjust policies and also think about future policies going forward. Great work, Samia, thanks so much. So now we've got Dr George Disney and so he's going to be talking to us about how can we make the NDIS more equitable, so I'll throw it over to George. Thanks, George. Come off mute, George, would be step one.

DR GEORGE DISNEY: Oh, sorry about that. Sorry. I was just saying lucky last. I'm glad you're all still with me and thanks to all the previous presenters for hearing about the really interesting work.

So what I'm going to talk through today is a brief introduction to some of our NDIS work that we've done and a key focus of our NDIS work has been looking at social inequalities in plan size and spending of the NDIS. This work was conducted by a fabulous team at the University of Melbourne with the Disability & Health Unit and Melbourne Disability Institute. Yi, Peter, Kirsten, Anne and Bruce all contributed a great deal to this work.

So today I'm going to talk through the motivation, so why did we do the work in the first place, and then the bit on methods really is about how we tried to rethink some of the previous work that had been done and to try and move thinking on in analysis of inequalities of NDIS data. Then I'm going to show a brief example of one set of the results that we have and then finally just talk through some of the implications of our project and the lessons of using this data.

Okay, so the motivation for the work that we did was it was concern that utilisation of NDIS plans, so utilisation is kind of use of NDIS plans, was low, so it was raised by the Productivity Commission and it was also raised in the NDIA quarterly report, so in June 2020, when we were kind of starting this work, 70% of people's allocated plans were being spent or used on services and supports and there was key differences by disability groups, so utilisation was low for people with a psychosocial disability and there was other key differences by demographic groups as well.

So at that point when we started the work most of the previous research had described differences in utilisation between groups and the NDIA quarterly reports had started at that point to look at variations in plan size across the country, so by area and in particular it looked at differences in plan size according to SES, social economic status, classification of each area. But, you know, just looking just at differences between groups, does that represent an inequity? So if you identify a difference in the data between two different areas, is that necessarily an inequity and related to barriers towards accessing the plans that people need?

Okay, so the first part of the methods that we kind of rethought was how do you measure utilisation and what is utilisation. So previously how utilisation could be measured was to take the total amount of spending in a particular group, so spending on services and supports for the NDIS, and then take the total amount in plans for that same group and then just to divide the two. So if you had ‑ you wanted to know what utilisation was like amongst all NDIS participants, you'd just get a column of data on all the spending, a column of data on all the plans, sum those two columns up and then divide them. And then that's where those figures that we previously mentioned before came about, so that's the 70% figure of utilisation.

But if you think about it, there are many ways that you could get that utilisation number to go up or down. So you could reduce plans. If plans were lower, spending stayed the same, that would increase utilisation. If you increased spending but plans increased by a larger amount, that could also end up in lower utilisation. And then also we were thinking is this actually a good measure because if you had really high utilisation, you know, so close to 100% or 100%, that could be indicative of people not having what they need in the plans. So we were really thinking through how can you measure utilisation and what does it actually mean?

So what we settled on was that we wanted to measure utilisation or plan size and spending at the individual level. You know, you can take summary measures and average over different groups in the population, but for the key bits of the analysis we wanted to analyse unit record individual data.

We also wanted to estimate plan size and spending separately because there might be different things that are causing different levels of plan size and different things that are causing different levels of spending, so it was really key that we measured them separately and also, as we previously mentioned, there's multiple ways you can get utilisation to go up and down ‑ you know, plan sizes could change, but spending could stay the same and that would result in a different measure of utilisation.

Okay, so the second bit of our methods is also thinking through well, what is a good level of utilisation or a good level of service use and we didn't really have a way of measuring that in the data because it's almost like you want to assess against the needs of individuals and we didn't have that in the data, but one way we thought we could get at what's a good level of service use or whether there are certain barriers to getting plans or being able to access services is to look at inequities. So compare two social groups within the scheme, so maybe the Indigenous population versus the non‑Indigenous population or people from low SES backgrounds against high SES backgrounds and work out whether there are differences in spending.

So from the qual literature and what we were hearing on the ground, we had groups we hypothesised could receive barriers in receiving plans and spending. That was key focus of our analysis, to estimate inequities.

The other key thing, as Zoe and Samia also mentioned, there might be other causes of plan size and spending that could be related to being a member of a group. I'll give you one example. So we know that age is related to larger plans, as people get older they on average generally need to have larger plans. We also know that the Indigenous population within the NDIS is younger, so some of the differences we observed for the Indigenous population might be down to the age structure of that group. So it was really important in our analysis that we used appropriate methods to make our comparisons fair and like for like.

So just to recap, we wanted to analyse plan size and spending separately. We wanted to consider the drivers and the causes of plan size and spending separately. We utilised unit record data on NDIS participants and then, having done that, it's perfectly fine then to use utilisation as a summary measure.

So here are our results where we focused on quantifies inequalities in NDIS plan utilisation, plan size and spending, and then we did some more modelling where we looked at whether increased use of support coordination could modify these inequities.

This is kind of like a summary diagram of all the populations we looked at, so it's a diagram that shows four target populations, so all people in the NDIS. We also looked at adults with psychosocial disability, adults with intellectual disability and children with autism, but we've bolded the left‑hand column to indicate there the results that we're going to show and the key comparisons that we made were the culturally and linguistically diverse community versus the non‑culturally and linguistically diverse community, the Indigenous population and non‑Indigenous population and low SES versus high SES. So they're the three inequities we're focusing on in the population of people with any disability type in the NDIS.

So here are the results. There's three graphs on this page. On the left‑hand side we've got a graph that's showing our inequity results for plan size and spending for the Indigenous population; in the middle for the culturally and linguistically diverse population; and on the right by socioeconomic status. So the dots at the top of the graph indicate plan size and as you can see on the left‑hand side the plan size for the Indigenous population after adjusting for other key causal drivers of plan size is higher than the plan size of the non‑Indigenous population. So the Indigenous population are receiving on average larger NDIS plans.

But then when we look at spending below, you can see that spending levels are similar, so the higher plan sizes don't translate into higher levels of spending, which results in a utilisation of 58% for the Indigenous population compared to 66% for the non‑Indigenous population. So it appears that there aren't necessarily inequities in accessing plan sizes for the Indigenous population ‑ in fact, maybe the scheme is taking into account some of the pre‑existing social inequalities people face when they enter the scheme ‑ but what is clear is that there are barriers to spending.

So that was kind of a finding that we weren't necessarily expecting. We were expecting groups that we hypothesised may face barriers to getting the plans that they need would have smaller plans and in fact that wasn't what we found. In fact we found that there was larger plans for the Indigenous population, in particular for the Indigenous population with intellectual disability, but where the inequities are arising is in the ability of people to be able to use those supports and access the supports that they need. So the high levels of plan size did not translate into high levels of spending, especially for the Indigenous population. For people with psychosocial disability that gap, the kind of Indigenous and non‑Indigenous gap, was much smaller but there was lower spending all round, so there was low inequalities, but as a group overall barriers to spending seemed to be high for people with a psychosocial disability.

So the next step of the project was to estimate how these inequities could be closed and I'm going to very briefly talk through how we did that. So one intervention that we modelled was what would happen if people who had access to support coordinators were able to use more help from support coordination. Support coordinators are workers funded via a person's plan who help participants connect NDIS providers and understand the scheme. So they could in theory remove some of the barriers to spending. And what we found was that if you really increase spending from support coordination, it could lead to increased spending, especially for the Indigenous population in the group.

So on to the last part of the presentation now. What were the implications of our study design and our approach for this project? So I think it's really important that we focus on barriers to spending of NDIS plans. So large amounts of social inequity seen in the scheme are about participants being able to find and access the supports and services they need and this was a particularly new finding different to some of the previous research that had been done. And the reason we came about with these results and these conclusions is the importance of really carefully designing your research methods and structuring your analysis in the way that you really are estimating the social inequity rather than simple description of the differences in the NDIS access between groups in the scheme.

If you want to read more about that, we've completed two reports. One was commissioned by the Department of Social Services and one was commissioned by the Department of Families, Fairness and Housing in Victoria. There's lots more results in those reports and some more results where we've used linked Victorian data that looked at inequalities in health for people with disability. That should be coming out later this year and then we're just about to start a similar project on NDIS utilisation for the Queensland Government. Thank you.

PROF. DENNIS PETRIE: Great. Thanks so much, George, great job. So yes, so I suppose with the NDIS data becoming available to analyse again there's a wealth of knowledge to kind of improve things there and I suppose, you know, George has been one of the first people to kind of get his hands dirty with the data and it takes a lot of effort to actually understand the data that's there and so I suppose he's spent a lot of time and knows a lot about that data and it kind of shows in his research.

Now I'd like to throw over to our fearless or one of our fearless leaders, Professor Anne Kavanagh, and so she's going to summarise some of the key messages from today. Thanks, Anne.

PROF. ANNE KAVANAGH: So I won't go over the findings. I think really what I wanted to just reflect on really, really, really briefly is that there is an underutilisation of data on disability, but also I think what we've hoped to demonstrate today is that researchers external to government may actually look at data in slightly different ways to government yielding different insights and a particular example I think of that is George's analysis of the NDIS utilisation data, which gave us kind of a slightly different ‑ using different methods than had been used by the agency where we were carefully looking at trying to match the populations and really understand what the drivers are of plan size and spending. It gave a slightly different interpretation than we might have seen from other more descriptive analyses.

I think Samia's example gives us a very important example about how data can be used to look at policy harms and benefits and I think it's very important in terms of holding government to account for us to investigate the impacts of these kinds of reforms like the ‑ that's just one example of the DSP reform, but she used a very neat way of analysing it to show pretty conclusively in my mind, and I'm sure there are many more harms that could have been shown to that reform to the disability support pension, we need to keep reminding governments that policy reforms are not necessarily neutral in terms of their impacts on people.

I think as we open up data and data has traditionally been held by the data custodians, not linked together and so forth, with the NDDA coming on board I'm really hoping that we see a new generation of research done where actually people with disabilities and representative organisations are able to see the potential of this data work and we actually start to work together to answer the key questions that are relevant to our lives.

I think the example, Nicola's example, that of the monitoring framework I think is a great example and I tweeted about it, how that monitoring framework actually came from was informed and developed by people with lived experience and so these questions again can start to be driven in that way.

I think it also demonstrates that actually what we need to do is invest in the capacity to do these kinds of nuanced analyses of disability data and recognise limitations for people in academia and outside academia as well as within government.

I'm sure there's lots of discussion in the chat and I don't want to take up any more time, but I just want to thank everyone. There's many more things we've done over the period of time of the CRE and very happy if you go to our website, you can see some of that, but very happy to be contacted about some of the work that we have been doing.

PROF. DENNIS PETRIE: Great. Thanks, Anne. We'll just take a pause there. So I suppose someone put in the chat about feedback from today and so we'd definitely love people's feedback on what worked, what didn't work, what could we do better for next time, different topics or ideas that you'd like to hear about or see. So if you can go fill out our survey and take a couple of minutes to do that now, that would be much appreciated.

What you can also do now is add any questions that you have from any of the presentations in the chat, and so that might be about particular presentations or questions on the data sources people use. So I think feel free to put your questions in the chat and we'll come back and we'll get the speakers to kind of respond to some of those questions ‑ so they've already been put there and some additional questions that people might ask. So yes, so you can just go to the link to the survey. It should take you there and, yes, please give us your feedback on what you've seen so far.

So I'll just ask all the speakers to turn their cameras on. So I suppose you've all probably been looking through the chat already kind of working out which questions are coming for you, so we'll see which ones come for you. So I suppose we might start with one of the questions that was brought up towards the end, which is about data sovereignty and about kind of including ‑ making sure that we include people with disability and people whose data that we're kind of using and how we kind of include them in the conversation right from the start of our research in developing the question all the way to interpreting the results as well. I don't know, Zoe, do you want to kick us off with discussion on that?

DR ZOE AITKEN: I think that's a really great question and thank you for bringing that up. I think it's something we need to start thinking about and having a discussion about it because it's not really happening at the moment, so I think that's something that lots of people, researchers, can work together with government departments and advocacy organisations to get that conversation started.

I think that's really important. Something we try and do in all our research is to co‑design it as much as possible with people with lived experience, but I think having that conversation about data is something else that we need to do and we need to start doing it now.

PROF. DENNIS PETRIE: Excellent. George, do you want to add anything to that?

DR GEORGE DISNEY: No, definitely agree with what Zoe said. It's really important that people with disability are included throughout the research process and, you know, we put a lot of effort into that but we definitely haven't got it perfect and got it spot on, so we're keen to listen and learn from people out there in the sector about how we can improve and how we can do that. And I guess, you know, feel free to contact us, you know. Emails online or we can make sure our contact details are posted in the chat too.

PROF. DENNIS PETRIE: Excellent. So I might throw a question over to you, Nicola, about the definition of disability and about especially disabilities that might be episodic and, you know, how we kind of capture them in our data when someone might report, you know, having a disability but then, you know, not report it in the next period, for example, and how we kind of best capture, you know, what's happening for those people in society.

DR NICOLA FORTUNE: Thanks, Dennis. Yes, that's a very good question and I think that the approaches for identifying disability in the ABS surveys do endeavour to be inclusive of people who have more episodic experience of disability. I'm not sure the extent to which that has been tested in the data to really determine whether certain people are missed by the current definitions that are used in those surveys or in other data sources, but yeah, I think another issue is when you're looking at the population of people with disability in Australia, you know, disability is a dynamic thing for individuals and certainly at a population level as well and I think it would be valuable to use the data sources that we have to dig deeper into that and to understand the dynamics of disability at an individual level and at cohort levels. I think having a better, fuller understanding of how the experience of disability changes and fluctuates over time will be really important, you know, for understanding policy implications for a whole range of different policy settings. So I definitely think it's an area for more research, but that's what researchers always say, isn't it?

PROF. DENNIS PETRIE: Yes, there's always more work to do, definitely. Zoe, I might throw over to you on that question, but also I suppose there was another question about like sometimes our research designs requiring the onset of disability or disability status to change, that kind of excludes people who might be born with a disability and so I just thought it would be good to get your thoughts on that and, you know, how we might not kind of exclude those groups from our analysis or how we might want to consider them differently to kind of think about what kind of is important for those people.

DR ZOE AITKEN: Yes, thanks, Dennis. That's a really, really important question. I'm really happy to talk about that because it's something we've been thinking about a lot and I was hoping someone would ask that question.

Back on to the question that Nicola was asked. I guess what we could say is longitudinal data allow us to examine some of those patterns, some of those patterns of people transitioning in and out of different disability states, shall we say, and reporting different levels of restrictions over time. So that's one way we can start to investigate those patterns over time, which is really interesting and underresearched.

Now, relating to the other question, you know, what I presented in my study, we looked at people who had acquired a disability when they were of working age. Now, that is definitely not a representative sample of people living with disability in Australia. We made that decision to try and get better estimates of the causal effect of disability on mental health and the effect operating through employment, but we acknowledge that those estimates only really apply to a small sample of people with disability. So what we try and do is we try and use triangulation of evidence, we try and use different approaches to answer slightly different questions to build a full picture. So some approaches might use a broad population of people with disability and use different methods to try and get an understanding of, for example, the impact of the employment on mental health for a broad population of people with disability, so we try and use different approaches and always keeping in mind who is the population that we can apply those findings to in every analysis that we do.

PROF. DENNIS PETRIE: Great. Thanks, Zoe. I might throw over to you, Samia. There was a question about, you know, your research design and, you know, for example I suppose, you know, in your analysis you compared the people who were just under 35 and who were kind of the targets of policy change compared to those people who were just over 35 and who weren't targeted, so I suppose there was a question about whether or not you considered using regression discontinuity, so whether or not you kind of look at the difference in outcomes as kind of people touch that 35‑year‑old and switch from being targeted versus not targeted.

DR SAMIA BADJI: Thank you. Thank you for this question. So yes, regression discontinuity analysis is another way to get great causal answers regarding policy questions. So one reason why it would have been a little bit difficult ‑ so basically we assumed that right underneath the age cutoff and those above are similar except for that kind of policy reform that happens when you turn 35 and there's no other reason why you're dispensed medication would change just because you turned 35, right, except for this reason. One reason was simply that the level of the granularity of the data that we had was kind of preventing us a little bit to do that because we didn't have the exact date of birth, so we didn't have the exact age, so it's not like we could flip around too much around this cutoff.

Another reason is that, for example, if you take those who are 33 years old, they're affected up until they're 35 and the same thing those who are 34 years old, they're affected up until they're 35, so they have this balance between taking a lot of people around the age cutoff and taking a little bit of people and so for this reason we have used difference in difference analysis and even with that, you know, we took 29 to 33‑year‑old, I'm aware there are other techniques where we could have taken people right below 35 but then you are making assumptions about ‑ you're basically taking several populations and kind of aggregating the average effect.

I'm sorry if this is technical, but yeah, there's a lot of discussion we are having behind it. I'm showing a nice graph, but there's a lot of things going on in terms of which method is best to use and technical details I didn't want to get into today, but yes, so we have considered it but we decided to use a difference in difference analysis. Thank you.

PROF. DENNIS PETRIE: Great. Thanks, Samia. Feel free to reach out to people's email addresses as well if there's more technical discussions you'd like to have with them, I'm sure they're willing to have those technical discussions. George, I might throw to you about the NDIS and about incarceration as well and that kind of tension between the data in terms of whether or not it includes people who have been or have come out of being incarcerated.

DR GEORGE DISNEY: I think it will include people in there, but whether we'll know where they live at that current point of time, whether they're incarcerated at that point in time, I'm not entirely sure about within the NDIS data. That's something I have to check.

Something that could be done, though, even if that data is not recorded within the NDIA researcher data is to link appropriate data to the NDIS data and then you would have detailed information about where an individual lives at a given point in time. If you had detailed information on the plan size and spending you'd be able to track whether there's changes in plan size and spending and access to services according to the setting someone lives in. I think it's a really great question and really important area of research given what we know that sometimes it's hard to access NDIS services when you're not living in your usual setting or when you're in hospital. Really important and underresearched part of the NDIS service use, I think.

PROF. DENNIS PETRIE: Great. Thanks, George. I might throw to you, Nicola, now. There's a question about how we might get better information on disability into our admin data. So, for example, you know, for that small section of population who answer SDAC, we can link it to their other records, but for the rest of the population who aren't in SDAC, so how do we kind of make sure that we do have good data to be able to split up these groups to better understand the issues at hand. So I don't know whether or not you had any bright ideas to solve the world.

DR NICOLA FORTUNE: Yeah, well, it's certainly a very good question and I think it's something that we should all be, you know, collectively working on. I think that ideally having a self‑report question about disability that's designed to be aligned with that SDAC broader definition of disability ‑ having a question in an administrative data set that captures most of the population ‑ for instance, you know, primary care data ‑ could be a really good solution. Of course, you know, the practicalities of making that happen are challenging, you know, how can you design a question that would be quite succinct and yet well aligned with the SDAC definition that could be asked of people in, you know, for instance a primary care setting and that would provide reliable data and there are all kinds of issues around the setting in which a question is asked that will affect people's willingness to answer that question. But I think that's an ideal to work towards and certainly something that's worth, you know, doing some development work on and I am aware of a couple of projects happening in relation to health administrative collections where there's an interest in capturing information, identifying people with disability primarily to be able to offer services better on the ground and I think that's another really important point to make in relation to administrative data sources that the primary reason for collecting data should be about providing better services on the ground and hopefully how you ask those questions and collect the data will then also be useful for, you know, statistical research. But, yeah, it needs to be able to deliver a benefit for people who are giving the information freely, there's got to be something in it for them in terms of getting better services. Thanks.

PROF. DENNIS PETRIE: Great. Thanks, Nicola. There's also a couple of questions about citizen data and how we might link kind of citizen data reported on accessibility in different communities and how we kind of might use that potentially linked with administrative data to kind of answer some of these questions about how accessibility impacts on outcomes for people with disability. I don't know, Samia, whether or not you wanted to answer that kind of maybe linking into your transport study and what were potentially some of the limitations represented to that transport study?

DR SAMIA BADJI: I'm not sure. The limitations regarding the transportation study ‑‑

PROF. DENNIS PETRIE: Yes, for example, I suppose we had transportation data on public transport but I suppose we didn't have much information on how accessible that public transport was for people with disability.

DR SAMIA BADJI: Yes. So we had ‑ like the data we had was very impressive. It was the result of a lot of work of one of our colleagues, which looked at what we have called accessibility but which was basically whether there was enough trains or buses going through a bus stop and this was already a lot of work and yes, there is not ‑ we did not have information on accessibility in terms of being used by people with sensory issues, for example, or in a wheelchair and so on, so it's limited information but even with this very aggregated and heterogenous way of measuring accessibility to public transportation we could still see differences between people with and without disability and we could use that. They were more likely to go to the GP, for example, more likely than those without disability if they had access to public transportation. But yes, it's an issue to not have all this great data set at hand and, yeah, if you have them, link them in and maybe we can work together.

PROF. DENNIS PETRIE: Yes, thanks, Samia. There's definitely a lot we can do. All these things take a lot of work. I know from my experience, getting into any of these data sets takes a long time to understand them and not only put them together. So there's definitely a lot of work that goes into it and it's not a quick process, should I say, often. We have a question here about gaps in disability employment data, so there's many reasons why people might not share disability‑related information about themselves when they apply for work in the workplace. We also find inconsistent definitions of disability in different contexts. We're seeing more and more counting heads in relation to employment targets, so I suppose the question is how do people feel about the usefulness of employment targets given that data may not reflect the real state of play. So I suppose, you know, we're kind of not measuring potentially everything, but we kind of still like counting heads. George, I don't know if you want to have a first go.

DR GEORGE DISNEY: I guess that topic isn't my expertise, but in general what I would say is that with admin data, as Nicola mentioned, the data is only a reflection of the data collection process, so if you have data on targets, that's what you've got, right. You don't have necessarily data on this perfect measure of employment that you're looking to get access to. So it's really important with any administrative data that whilst it's incredibly valuable data, it only reflects the data collection process, in comparison to survey data which is completely designed for research, but then there's big drawbacks of survey data as well. A sample of the population, it may not include really detailed information about what happens over time. You might only collect the data once a year. So that's what I would say about that. So it's really down to the analysts using the subject matter expertise and engaging with policy makers, engaging with people with disability to really understand the data that they've got at hand.

PROF. DENNIS PETRIE: Excellent, thanks, George. We've also got a question about how we can make sure that all this evidence that we generate kind of goes towards changing policy and so therefore that we kind of get this virtuous cycle where people can see the value of giving their data so therefore we get better data to inform policies and then it actually changes people's lives for the better. So I suppose how we kind of link those things up ‑ I don't know, Nicola, whether you want to have a go. It's a difficult one I must admit, about how we try and make sure that our research just doesn't sit in a publication online but it actually changes policy.

DR NICOLA FORTUNE: Yeah, I think that's a very ‑ it's a really important question because it's a wasted investment if we do all this research and it doesn't actually have an effect out there in the world.

I think that there are probably, you know, a lot of fronts that we can all be working on to make that research translation work better and I think that, you know, relationships and communication between all the people involved is really fundamental. So people with disability, disability representative organisations, researchers, policy makers, we all need to be, you know, talking to each other. I mean, there are so many ways that ‑ so many platforms where you can make research findings available now and I think that's fantastic because research is not just published in academic journals anymore, but it can also be a bit overwhelming because there's so much research all over the place. I think having a way to sort of bring research together into one repository could be really valuable.

I think that Australia's investment in the National Disability Research Partnership is really important and I think that over the coming years under that initiative we might see attention to sort of how to make this work better and how to connect people up and how to have ‑ how to make research easier to find. Thanks.

PROF. DENNIS PETRIE: Excellent. Thanks, Nicola. So I suppose we're coming to the end, so I might draw the Q&A to a close, but if we haven't answered your question, please feel free to either email the speakers or email our generic email box and we'll make sure it gets to the right person.

I must say that from the CRE's perspective, in the last six years we've put a lot of effort into kind of pulling the data that is available together, trying to increase the capacity in Australia to do disability research with this data and so lots of our bright young people who we've got here today have been bringing their skills to these questions and so it's really important that we continue to build this capacity, to analyse the data that we have, to change policy, but I think there's definitely lots of things that we have to keep doing. So as part of this we've had lots of input from our partner advisory group from advocacy groups and government organisations as well and so that's been really, really valuable to us. So I think we definitely have to keep this conversation going.

So yes, so I'd like to thank everyone for coming. If you have any further comments, please feel free to email us, but yeah, I'd like to thank everyone and like to thank the speakers as well. So excellent job and so, yes, I'm sure that we'll have lots of questions and we'll have lots of work that we'll need to do in the future. But yes, thanks so much, everyone.