

Including Trans People in Research Webinar

Video Transcript

BEGIN TRANSCRIPT

Ada Cheung: My name's Ada Cheung. I'm a clinician scientist, and I lead the Trans Health Research Group, and together with Dr. Sav Zwickl, my colleague and research fellow, we're so delighted that you've joined us today to talk about our new guidelines on Including Trans People in Research: A Practical Guide to Collecting Data on Gender and Sex. And we're so glad that you're here with us.

We want to start by acknowledging that we're all on the lands of the traditional... we want to acknowledge the traditional custodians of the unceded lands where we're all working from and joining today, and where this research has taken place. We pay our respects to the Elders, both past and present, and to all Aboriginal and Torres Strait Islander people here with us today. We also acknowledge that trans people are ancient. They have existed throughout the history of time. These lands are the home of the oldest continual culture, and therefore the home of the oldest examples of gender diversity.

We just want to highlight that we're going to talk about some challenging topics that trans and gender-diverse people face, including depression, suicide, discrimination, and violence. And, if this causes you any distress, please feel free to take a break, or step out of the meeting at any point. We've also got some contacts in this slide for organisations that provide support.

So, this is what we're going to talk about today, in this seminar. We're going to talk a bit about why we develop these guidelines. We're going to paint a little bit of a picture about trans health in Australia. And we're not going to assume any prior knowledge. A bit about the impact of trans exclusion in research, and how all of us here today can be allies to the trans community. And as researchers, people working in clinical or health services, or public health research, it's so important for every one of us to be an ally.

So, we started developing these guidelines about 12 months ago, because we're often approached by researchers from all sorts of fields. About, what how do we include transgender people in our research? How do we ask the questions about who is trans, and who is cisgender? And so, we had researchers, from people who are working in cancer, people working in arthritis, people working in neurology, asking us for advice about how to include trans people. And so we thought, there really isn't any guidelines out there. Secondly, there are many sex... There are many diseases that have sex specific prevalence. And because of that, for example, cardiovascular disease is higher in men. Autoimmune disease is higher in women. We don't know how gender-affirming hormones impact on any of these diseases or health conditions with sex-specific prevalence.

There's also been, recently, an NHMRC and MRFF statement on sex, gender, and inclusion of people with variations of sex characteristics. The draft statement is currently out for public consultation, and will be published in its full form very soon. We're from Victoria. And there's also local state-based equality policies, like the gender equality policy, that insists that anyone working in a health service needs to ensure that the services that we provide for the public are reflective of men, women, and gender-diverse people. And it's also best practice to consider the impact of our research on marginalised groups. Including those who are gender-diverse, or have sexual diversity, and research ethics committees are going to be asking more and more about how these... Researchers are considering the impact of their research on these marginalised groups. And so, we wanted to create a very easy, short, clear resource, as well as a quick three minute video, which we'll share with you shortly, about, how do you include trans people in your research?

Now, when I talk about trans, I'm referring to anyone. And I'm going to use trans as an umbrella term. I'm going to use it to refer to anyone who's got a gender different from that recorded for them at birth. Many people will use different terms; transgender, trans and gender-diverse, transsexual. But I'm going to use the umbrella term trans to refer to anyone with a gender different for them recorded at birth. And we know that being trans is not a mental health disorder, but a natural part of human diversity. And, whilst trans people can affirm their gender in many ways, whether that be socially, legally, or medically, we know that medical gender affirmation in particular can reduce mental health distress, improve quality of life, and reduce suicidality. And, when we surveyed about a thousand trans Australians, we found that roughly a third have male identities, roughly a third have female

identities or are trans women, and roughly a third have non-binary identities. So, trans women are people who are recorded male at birth who have a gender that's a woman. Trans men are people who are recorded female at birth, and have a gender that is a man, and non-binary people may be recorded male or female at birth, but they have a gender that doesn't fit into the typical male or female category. They may feel that they are in-between or outside of the two binary categories, and there's various terms. So, non-binary is used as an umbrella term, as well as an individual gender identity.

In Australia, we don't count trans people in the census. But, hopefully that will change. If we look internationally at research of population-based samples... In youth, children and adolescents, about 2.5 to 8% report that they have gender diversity. If we look at adults, it's anywhere from 0.5 to 4.5% amongst adults. And so, that's anywhere from 250,000 up to potentially 1.4 million trans people in Australia. So, why do we do research in trans health? So, my background is that I'm an endocrinologist. And I saw, about 6 or 7 years ago, this enormous clinical need. So, there was a huge demand in gender-affirming health services. So, this is some data that's quite old now. But back in 2016 we saw, over a 5 year period, a rapid increase in people seeking gender-affirming hormone therapy. And this is data from my clinic in Heidelberg. But it mirrors that being seen worldwide. It mirrors what's being seen at the Royal Children's Hospital, in paediatric services, and all international gender health services. We don't think it's because there are all of a sudden more trans people. But we do hypothesise that this is related to increased visibility of trans people in media, social media. There's now access to information. There's language. I've had patients say to me, a 70 year old patient say to me that, back in 1950, they knew that they were a woman, but they had no language to describe it. It's only now that there is language that they can actually express their gender. There's reduced stigma, although we still have a long way to go, and there are services available. So, people know that they can access healthcare.

We surveyed trans Australians and found that over 70% had diagnosed depression, anxiety, and 63% had self harmed. And an alarming 43% had attempted suicide. And this is far higher than any other population in Australia. Higher than Australians with depression, higher than Indigenous youth. And recent research has suggested that completed suicide is up to 2- to 5-fold higher than the general population. And in Victoria there's a current coronial inquest into trans and gender-diverse suicides recently. And so... We don't think that... Well, we know that being trans is not a mental illness in itself, and a lot of the psychological distress is related to discrimination. Widespread discrimination in almost every aspect of life. So, our research participants told us that 23% had been physically assaulted. And I've certainly had patients been punched on the train coming to see me in clinic. 68% had been verbally abused. People had discrimination accessing housing, government services, and employment. So it's very, very hard to get a job as a trans person, and that leads to socioeconomic disadvantage. And most alarmingly to me, as a doctor, is that 28% had experienced discrimination accessing healthcare. We have patients being turned away, turning up to waiting rooms and being turned away for being trans. And the negative environment that we are encountering socially leads to a lot of hate. And so this year, in 2023, there's been a Fuelling Hate Report published, showing an exponential rise in anti-trans abuse, harassment, and violence.

So, in addition to gender dysphoria, where people feel this marked incongruence between their physical body and their gender, which we call gender dysphoria, trans people have many other barriers to health. They are facing alarming rates of depression and suicidality, employment discrimination which leads to socioeconomic disadvantage, housing discrimination. There's high rates of homelessness, street harassment, physical, verbal, and sexual abuse. There's political footballing in the media, and by our politicians. There are barriers to accessing basic medical care, whether that be GP care or gender-affirming care. And, even when people can access healthcare, there's a lack of research to guide care. And so, because of this clinical need, these enormous barriers to health, and a low level of research evidence, we established the Trans Health Research Group in 2017, and we've been very privileged to grow and grow over time.

All of our research is co-designed. So, half of our team now are trans people themselves. These are doctors, and post docs, and PhD Students who are trans. And so, we embed community with everything we do, so all of our projects are relevant and designed, delivered, and run together with community.

We focus on 3 main priorities. On the left, improving mental health and wellbeing, because suicide prevention is a public health crisis at the moment for the trans community. We also focus on, how do we best deliver health services to the trans community? Because accessing healthcare is a major challenge. And thirdly, because I'm an endocrinologist, and I love hormones... And there's lack of research in gender-affirming hormone therapy, we are doing all sorts of projects related to, how do we best deliver and understand the effects of gender-affirming hormone therapy? We're looking at the effects on fitness, muscle strength, immune function, heart function. How do we best deliver testosterone, masculinising, or feminising hormone therapy? And we always communicate all our research back into community.

So, we focus a lot on community engagement and science communication, so that those who need the information can access it. So, all of our projects have a goal to improve the health and wellbeing of the trans community. And our project today that we're going to present to you is not specifically a research project, but it's a project that we hope will improve the health and wellbeing of the trans community by getting researchers from all sorts of disciplines to count and include trans people. So I'd like to hand over to Dr. Sav Zwickl, who will tell you a bit about how every one of us can be an ally to the trans community. And the trans community need allies because they're always going to be a minority of the population.

Sav Zwickl: Thank you so much, Ada. So, in terms of how we can be allies to trans people in research. Well, firstly, we need to look at the impact of exclusion from research, and fully appreciate what that can mean for the trans community. So, trans experiences are rarely accurately reflected in data collection, and this inaccurate representation, or exclusion, of trans experiences from research can have a real impact on both individuals and the community. So, as a trans person, I can speak from personal experience that, many times when I see surveys, the gender options aren't quite right. They don't represent my experience, and that can be quite distressing, or at the very least frustrating.

Not collecting data in a way that accurately represents trans people can also exacerbate marginalisation. As you've heard from Ada, trans people are facing a lot of different challenges in their daily lives and not including us in research can add to that, and in turn cause health disparities, and these clear knowledge gaps when it comes to trans people and their health, their wellbeing, their daily lives. In turn, when we don't have the research, this can lead to inefficient allocation of resources, and public policies that exclude trans people.

So, I just want to take you through a bit of a timeline here in Australia, when it comes to trans inclusion in records and in research, because it's been a really long process, and the progress has been quite slow. So, it was back in 1986 that the first trans person in Australia was ever allowed to change the gender marker on their identification. It wasn't, however, until 2011 that we saw the introduction of a third gender category, and Australia was actually the first country in the world to introduce a passport with an X gender marker. That was followed 2 years later, in 2013, by Australian government guidelines on the recognition of sex and gender. And that, too, included a third gender category. In 2020, the ABS released their standard for sex, gender, variations of sex characteristics, and sexual orientation variables.

However, what we've seen in the last 3 years since that release is, there hasn't been the uptake that we kind of hoped for, in terms of people who are researchers including those standards within their research. And even ABS themselves, in the 2021 survey, didn't follow their own guidelines and, to quote the article that I've got on the screen there, it was garbage data. Essentially, the questions were quite nonsensical, and it meant that trans people weren't included in the census. And as Ada mentioned, the NHMRC have just released a statement regarding sex, gender, variations of sex characteristics, and sexual orientation. And so there's gonna be an increased demand for researchers to include trans people accurately in their data. So, we really want you to see yourselves as trans allies, and you all can be. And, as health researchers and scientists, we really want to improve lives of others. That's why we do what we do, why we're so passionate about the work that we do. And a lot of that is around language. So, the questions that you ask and the terminology that you use. And inclusive language can go a really long way to convey visibility and validity to trans people, and to build trust and engagement in research. The increase in trans inclusion will most definitely generate novel data, and we expect to see that some of that will demonstrate inequities across numerous research areas. And in turn, this novel data can be used to support requests for funding for resources and services to improve the lives of trans and gender-diverse people.

So, without further ado, we'd like to introduce you to these research guidelines. We have developed written guidelines, it's a short PDF, and accompanying that is a three-and-a-half minute video. So, I'll take you through the key aspects of those written guidelines now.

So firstly, we want to acknowledge that this project would not have been possible without the support of a Diversity and Inclusion Grant from the Faculty of Medicine, Dentistry, and Health Sciences at the University of Melbourne. And these guidelines make recommendations that are based both on the ABS standard as well as TransHub, which is a website and resource created by and for trans people by the ACON team in New South Wales.

So, the key aspect of collecting data on gender and sex is what we call a two-step approach. That is, there's two key questions to ask that will enable us to accurately capture the experiences of trans people. So, the first question captures the participant's current gender, and the second question captures the participant's sex recorded at birth.

So, in detail, the first question says, How do you describe your gender? Gender refers to current gender, which may be different to sex recorded at birth, and may be different to what is indicated on legal documents. We acknowledge that you may have multiple descriptors for gender, or your experience of gender may be fluid, but for research classification purposes, please select the option that best reflects your gender. There are then five options. Man or male, woman or female, non-binary, a different term with the option of a free text write-in, and prefer not to answer. That's followed sequentially by a second question. At birth, you were recorded as, with 4 options. Male, female, another term with a write-in option, and prefer not to answer. And so we're going to go through, Ada and I, as examples of what this might look like.

Ada Cheung: So, for example, for me; How do you describe your gender? I would select, I'm a woman. At birth, I was recorded as female. And so, from these two questions we can work out that Ada is a cisgender woman.

Sav Zwickl: For myself, how do I describe my gender? I am a non-binary person. And at birth, I was recorded as female. So for me, I would be classified as a trans person with a non-binary gender. And I was recorded female at birth. So, with this two-step approach, we can... Any researcher can classify participants as cisgender or trans. And it allows for all kinds of variations and experiences to be accounted for and analysed appropriately.

So, for example, you might want to look at women of all gender experiences. From those two questions you can work out who all the cisgender and trans women are in your data set, same as you can look at all trans people, all trans people within non-binary gender, or cisgender people. So, there's all kinds of variations there. So, we've just gone through the key aspects of these written guidelines which is around those two questions. But in addition, in the written guidelines, we provide information such as what Ada talked about. The definitions, some of the research around discrimination. And in addition, we provide links to excellent resources on how to talk about body parts. Again, that comes back to language. There there are gender-neutral ways to talk about body parts, and that can be an important part of affirming trans people as well if that's appropriate to your research. We also provide links to the standard of how to ask about variations of sex characteristics, otherwise known as intersex, and sexual orientation. In the guidelines, we also provide links to key Australian trans health research, so you know what research has been done in the past, as well as national and international standards of care for medical treatment of trans people, so that you have access to what is considered best practice in terms of the medical treatment of trans people. And we also provide links to LGBTIQ-specific research ethics committees, namely those at ACON and Thorne Harbour Health in Victoria. And they are an excellent resource, in terms of providing you feedback about LGBTIQ inclusion.

The second thing in accompaniment with these written guidelines is a video. Part of the motivation for creating this video is, we thought, y'know, there's only so much that words on a page can do. And sometimes what really motivates people is hearing stories from people themselves. And so, we'd like to introduce you to this video. It's only three-and-a-half minutes, and you'll get to meet some wonderful trans community members.

BEGIN SHORT VIDEO TRANSCRIPT

Narrator: Have you heard the word transgender before? You may have seen it defined in a few different ways. Let me give you the simple version. Transgender is an umbrella term that describes people whose gender differs from what was presumed for them at birth and covers a large range of genders, including trans man, trans woman, non-binary, genderqueer, Sistergirl, Brotherboy, and more. Being trans is a natural part of human diversity. Trans people have existed for a long time, including in Indigenous communities, but we're often not counted when it counts the most; in research and in data. There's no right or wrong way to be trans, and no one trans experience. We have a diverse range of intersectional identities and experiences, and experience marginalisation in areas of life such as health, employment, education and housing. So, collecting data and information about the trans community is important. Let's look at why.

Text on screen: First question, have you experienced harassment or discrimination as a gender-diverse person?

Dr Camelia Rose Walker: Yes. [laughs] I mean, um.

Bridget: I don't think I know any gender-diverse person who hasn't experienced harassment or discrimination.

Dr Camelia Rose Walker: I regularly get harassed on the street by people.

Fin: Ogling and the leering.

Ty: You shouldn't exist or that you don't exist.

Ricki: He was kindly enough, wrote on the referral sheet, "Please refer to Ricki, not Rick. My patient is trans woman." The nurse came to call me for my appointment and called my male name. My heart sank.

Text on screen: What does it feel like when research questions aren't trans-inclusive?

Dr Camelia Rose Walker: Being excluded in data collection, it doesn't feel good.

Ty: I have to put a gender that I'm not. I have to put a name that is not my name.

Fin: It made me feel like I was being deceitful.

Ty: Basically, I'm lying on everything that I have to fill out. I guess, if that was reversed and cis people were lying on forms, like, that's like fraud.

Dr Camelia Rose Walker: It is quite a stressful time and it can be really overwhelming. Um, yeah.

Narrator: So, how can we collect data that's meaningful? It's easy. When conducting population research or assessing trends in the delivery of programmes and services, ask these two simple questions: "How do you describe your gender?" and, "At birth you were recorded as." Using this approach allows for data from people of all genders to be accounted for and analysed appropriately. Being counted in something like data doesn't go unnoticed either.

Ty: I think it would be a massive win all 'round. People are going to be getting accurate data.

Fin: So easy to do just two boxes on a form.

Dr Camelia Rose Walker: We will suddenly be able to know how different conditions affect trans people.

Bridget: Actually make sure that interventions are effective, that policy is effective.

Ricki: Adequate health services and developing appropriate care spaces.

Ty: I think it's a huge win for a very small change.

Fin: To improve the lives of many. There's no reason not to.

END SHORT VIDEO TRANSCRIPT

Sav Zwickl: So, thank you everyone, for coming. I realise we're almost out of time. So again, we just want to thank everyone who was involved in the design and implementation of these guidelines. Including the Faculty of Medicine, Dentistry, and Health Sciences at UniMelb, for awarding us with a Diversity and Inclusion Grant. Many dozens of trans people and trans allies who gave their time and expertise to this project. Our partner organisations TransHub and ACON. Endorsing organisations, the Australian Professional Association for Trans Health, and Thorne Harbour Health. Sav Zwickl: And everyone involved in video production and participants, including Rudy, snack drawer team, Bridget, Camelia, Fin, Ricki, and Ty. If you want to get in contact with us, you can find us on social media. Trans Health Research. Our email address is on the screen there. And the guidelines and the video are both up for download on our website. transresearch.org.au, and you can use that QR code, and that would take you there directly. We really encourage people to share these guidelines widely. You are more than welcome to host them on your own websites. We really want to encourage, obviously, greater trans inclusion in research. So, thank you everyone for coming along.

END TRANSCRIPT