

Beyond Undetectable Symposium (focus on achieving health equity for all people at risk of, or living with, HIV)

Thank you and good morning.

I would like to begin by paying my respects to the Wurundjeri peoples of the Kulin nation, and Elders, past and present.

And I also pay my respects to the inspirational Elders who have, over decades of passionate work and advocacy across Australia --- laid the path that we tread today.

In recognition of our cultural practices, I want to acknowledge that during my presentation I will be speaking the names and sharing pictures of Aboriginal and Torres Strait Islander peoples who have passed.

I am a proud Narrunga Kurna woman, from the Yorke Peninsula in South Australia... you can see on this slide, my Country, and the mission that I grew up on.

And I am the CEO of the Lowitja Institute – Australia's only national Aboriginal and Torres Strait Islander community-controlled health research institute.

In the 25 years since we began -- we can proudly say that the Lowitja Institute has changed the narrative in Aboriginal and Torres Strait Islander health research... though not without a fight!

This includes supporting Indigenous research --- and researchers --- focusing on HIV.

You can see a handful of our relevant research on this slide.

We know that meaningful translation of our research is critical to our work.

One of the ways we do that is via our International Indigenous Health and Wellbeing Conference.

Our latest conference was held just a few months ago, bringing together twelve hundred people, including Indigenous experts from across the globe.

And we were very proud to present one of our prestigious awards to Professor James Ward, who many of you will know -- or know of.

It was a well-deserved acknowledgement of his long-standing work and leadership in urging stronger HIV global action for Indigenous peoples.

I am very pleased to see your symposium title, which is Beyond Undetectable.

Your meeting is of course not just about the importance of reducing viral load, but also about overall quality of life – and this is relevant to our work at Lowitja Institute -- in pursuit of a healthcare system that supports wellbeing and equity -- not just the detection of disease.

For me though, the word *undetectable* also resonates on other levels... particularly as we seek in this session to dig down into inequities in health and health care.

The word 'undetectable' speaks to me of communities and issues that are not on the agenda – of that are so-called "hard to reach".

It speaks to me of a population too small to be seen or heard, of medical and health education that barely mentions us...forgotten... and a specialist workforce that is often unacknowledged, like our Aboriginal health workers are so often..

Of a community where there are inequities in: prevention, testing, diagnosis and treatment, *before* we even get to quality-of-life issues.

Aboriginal and Torres Strait Islander people have long been undetectable in this country... unseen, and – perhaps even more after tomorrow – unheard.

So how do we shift that?

First up, let me touch on equity...

I'm sure you've all seen this image --- or variations of it. Yet still it raises many questions for me ... even once we've provided the extra steps ... and removed the fence...

Who is actually on the playing field? Who isn't?

Who is umpiring?

Who establishes, governs, and then monitors -- the club rules?

And of course, because – as you all know well -- intersectionality is at the heart of these discussions: where is the diversity?!

Just to step into the concepts of equality and equity: 'equality' is about treating everyone the same to get the same outcome. However, equity understands that we don't all start in the same place.

It's about acknowledging where people are at now – meeting them there ----and giving them what they need.

And equity acknowledges the systemic and institutionalised differences in how people were --- and are --- treated, compared to members of the dominant culture.

Equity takes into account how "normal" was established in this country.

How colonisation ignored our ways of knowing, being, and doing --- an historical injustice which has ongoing intergenerational impacts for us all.

Which brings us to the question of health justice, or, of course, what we are really speaking about, which is health injustice.

For Aboriginal and Torres Strait Islander people, injustice is not abstract---- it is deeply real---- and deeply personal.

It is about Ms Nelson, a beloved 37-year-old Gunditjmara, Dja Dja Wurrung, Wiradjuri and Yorta Yorta woman.

She was a mother and a grandmother who was put in prison after being arrested for shoplifting – and she died alone in her prison cell here in Victoria – after pleading for help about 40 times.

I'll give you a moment to read the coroner's words.

Injustice is also about Ms Williams, a 27-year-old Wiradjuri woman, who was 22 weeks pregnant with a son when she died of septicaemia at Tumut Hospital in New South Wales in 2016.

The coronial inquiry into Ms Williams' death found she went to hospital 15 times in the months before she passed away without receiving a referral to an expert.

Sadly I could give you more cases...

Because we have a deeply entrenched pattern here--- where our people die from preventable causes within racist systems — in each of these cases -- within arm's reach of life-saving care that was denied them. They were ignored.

Ms Williams, who sought hospital care 15 times...

Ms Nelson, who called for help 40 times.

We receive injustice, repeatedly, not just from health systems – but also, in an irony all too familiar to colonised peoples, from justice systems.

The intersection of these systems is a key concern for the Lowitja Institute – as it is, of course, in your work too.

In those systems that imprison our mob --- at such disproportionate rates -- they are exposed to much higher risks of HIV transmission... and harm minimisation, if it even takes place, is piecemeal.

As you all know, no jurisdiction in Australia has reached full compliance with the United Nations' 15 key HIV risk-minimisation interventions for prisons.

It's our mob who are most affected by these failures.

And then, in the aftermath... when something inevitably goes terribly wrong... the settler state absolves itself of responsibility.

Perhaps it admits, unwillingly, that “unconscious bias” has played a part.

But never systemic, institutionalised racism! Nothing to see here... undetectable!

After all, those institutions probably have an internal policy “against racism”!

So these preventable deaths are inevitably explained away to a kind of “personal responsibility”, where... either “you should have spoken up more” ... or “they wouldn't have died if they hadn't – allegedly – committed a crime.”

I haven't worked specifically in the HIV sector, but I was for a long time a nurse who got to see and hear how systems works... so, I know you don't need me--- to tell you ----that people with HIV are all too familiar with this type of treatment.

Because if having HIV can be framed as their fault – for having unprotected sex or injecting drugs – the system is off the hook...

Poor care pathways are justified.

No injustice to be seen. Undetectable!

But a system like this ---is unjust--- and it puts us all at risk it puts us in situations where we don't feel we have the rights – or that we can speak up...

Where we are judged because of who we are...

Where we are blamed for our illnesses or injuries...

Where many services are not safe for us.

For Aboriginal and Torres Strait Islander people, that's why of course we need more of our mob providing healthcare...

But we also need the mainstream system to be culturally safe.

We should be able to go to any hospital --- any health service --- and not encounter racism.

That's the professed vision of the National Aboriginal and Torres Strait Islander Health Plan.

It's an important vision... But I am not sure whether our system knows what racism is: what it looks like, what it feels like, what it produces, and most importantly --- how to measure it.

Because, as this Lowitja Institute discussion paper pointed out, there is an inherent contradiction, in seeking a health system free of racism in a society that's founded on it...

So how *do* we achieve health equity?

We are starting to see a few green shoots germinating where HIV is concerned.

I'm sure some of you here today have been involved with them!

In New South Wales, it's wonderful to see how Positive Life organisation co-designed the Health and Needs Assessment for our mob living with --- or at risk of --- HIV:

This was done in partnership with the Positive Aboriginal and Torres Strait Islander Network and BlaQ,

And nationally we saw Health Equity Matters publish "Us Mob and HIV" in partnership with the Ah-NOOK-an-ah National Aboriginal and Torres Strait Islander HIV Alliance.

But – what comes next?

Which other mainstream harm-minimisation organisations will step up to the plate and put us in the driver's seat?

Our people and organisations have made powerful calls to the broader community to play their part in dismantling racist systems...

To play a role – specifically -- in *anti*-racism.

By developing models of care that ensure nobody is left behind...

And by following the plethora of evidence that shows us, if healthcare is to work for our peoples, there must be a flip – from delivering care "REGARDLESS of culture" – to delivering care with culture at its *centre*.

Because our cultures are not something we choose, or something we can turn on and off at will. They are the core of who we are.

Which of course brings me to this moment in our country's history... this defining moment of tomorrow's referendum on an Aboriginal and Torres Strait Islander Voice.

I cannot speak of health equity without urging you to vote Yes to this very simple and profound ask that we make of non-Indigenous Australians.

To be recognised and to be given a Voice.

And I hope what has resonated with you today is the cruelty of silence – the torment of powerlessness: the harm that comes from not being heard... from the cries of a woman in abject pain in her prison cell... to the poorer policies and services we endure, because we are not sitting at the policy table, where people believe they know what's best for us.

There are not many moments in life where we get to stand up and say yes to fundamental national change.

So I say: History is calling, and I hope you will walk with us into a new future, where we are not just detectable, we are enshrined ...

Thank you.