

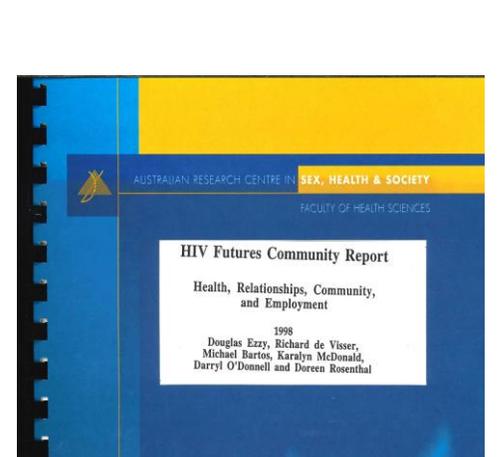
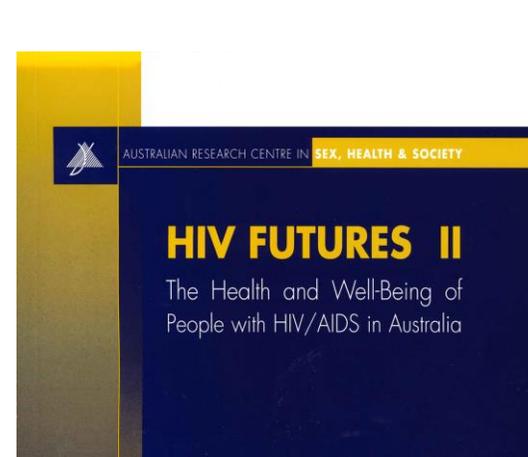
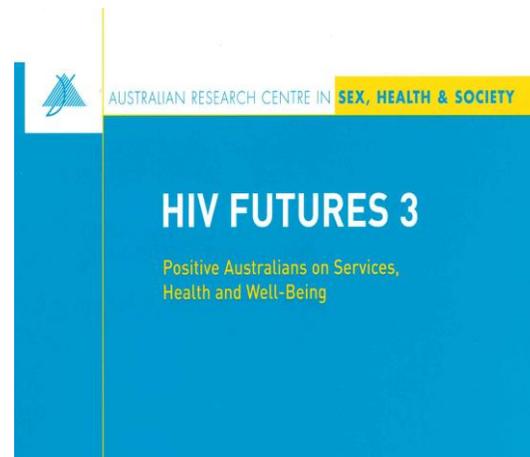
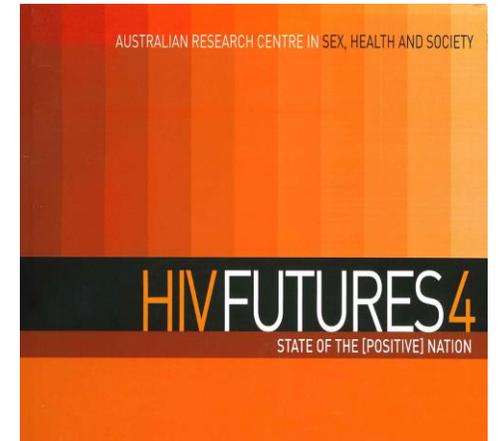
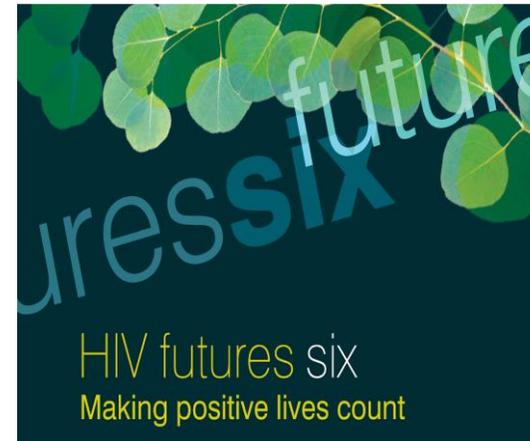
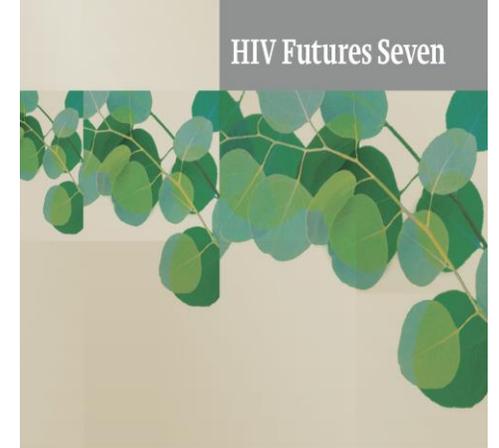
napwha national association of
people with HIV australia

Understanding PLHIV experience through the HIV Futures study

Dani (Daniel Putra-Jaya Sudarto, he/they), Social Worker

Dr John Rule, Senior Research Manager

Nine generations of HIV Futures

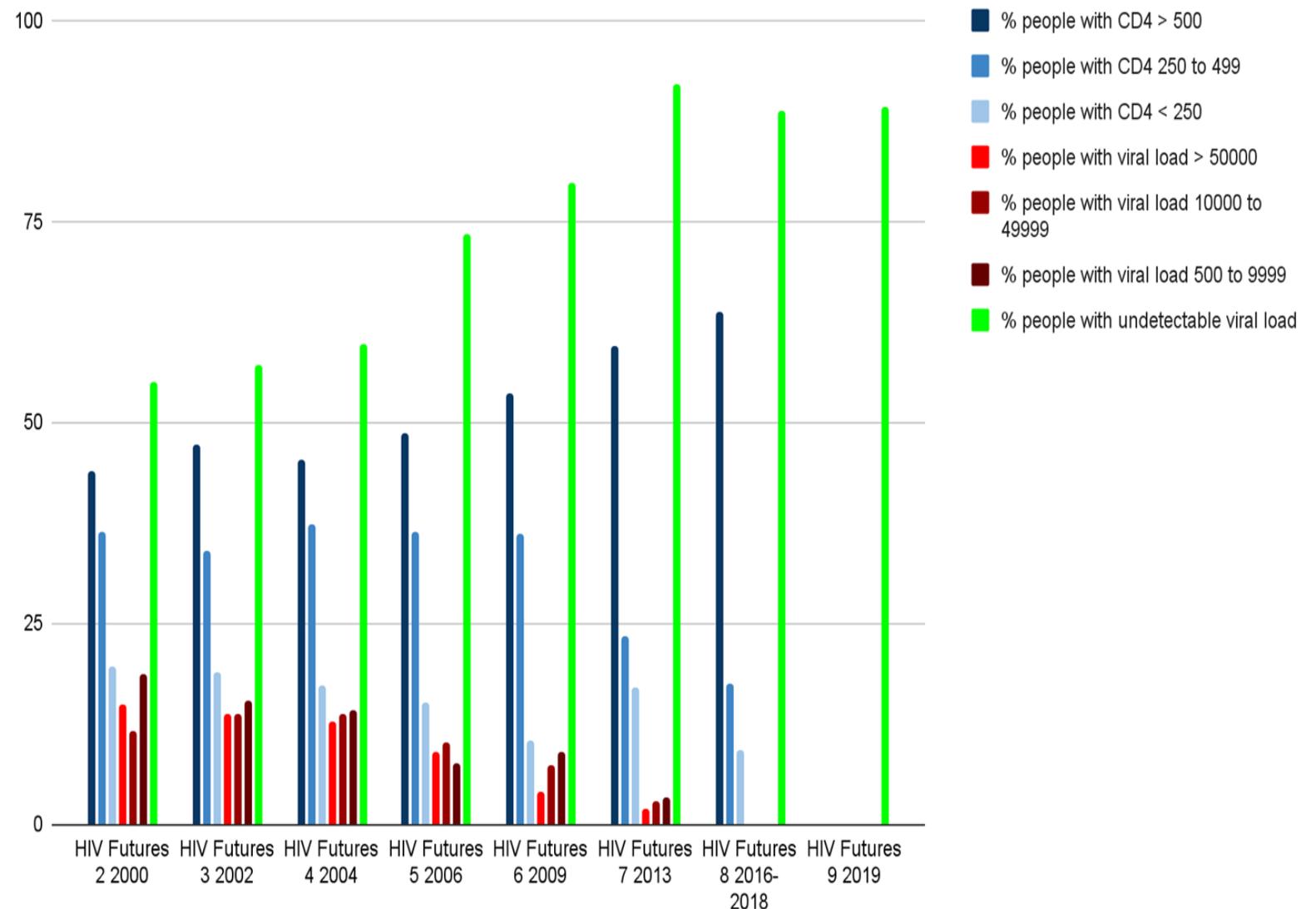


HIV Futures 2 2000 The Health and Well-being of People with HIV/AIDS in Australia

41.3% people reported having a CD4 count above 500;

54.9% people (those who were on ART) reported having an undetectable viral load

Results of most recent serological tests (percentage of people from total sample)



HIV Futures 3 2002 Positive Australians on Services, Health and Well-Being

41.3% people reported
having a treatment break.

- People decided to take treatment breaks for various reasons. The general trend is that there appears to be less people having treatment breaks as the year progresses. In **HIV Futures 2 2000** **46% people** reported having a treatment break. Fast tracked to **HIV Futures 7 2013** only **27.9% people** reported having a treatment break at some point of their HIV care. From **HIV Futures 8 2016** onwards, this topic was no longer explored.

HIV Futures 4 2004 State of the (Positive) Nation

Increased attention on
Hepatitides as a
comorbidity with HIV, in the
study.

- In **HIV Futures 4 2004**, there was an increased attention on Hepatitis. This topic was now expanded in that the study now included multiple hepatitides infection. Additionally, discussions on testing practices, diagnosis, treatment, hepatitis related health issues and monitoring were more comprehensive compared to **HIV Futures 3 2002**. **HIV Futures 1 1998** and **2 2000** did not cover hepatitis. This topic was last discussed in **HIV Futures 7 2013** and ceased to be discussed in **HIV Futures 8 2016** and onwards.
- Throughout **HIV Futures 3,4,5,6**, and **7**, the comorbidity between HIV and Hepatitis was presented as a risk factor of one infection affecting the other as well as an important factor in PLHIV's decision making process around their ART.

HIV Futures 5 2006 Life as we know it

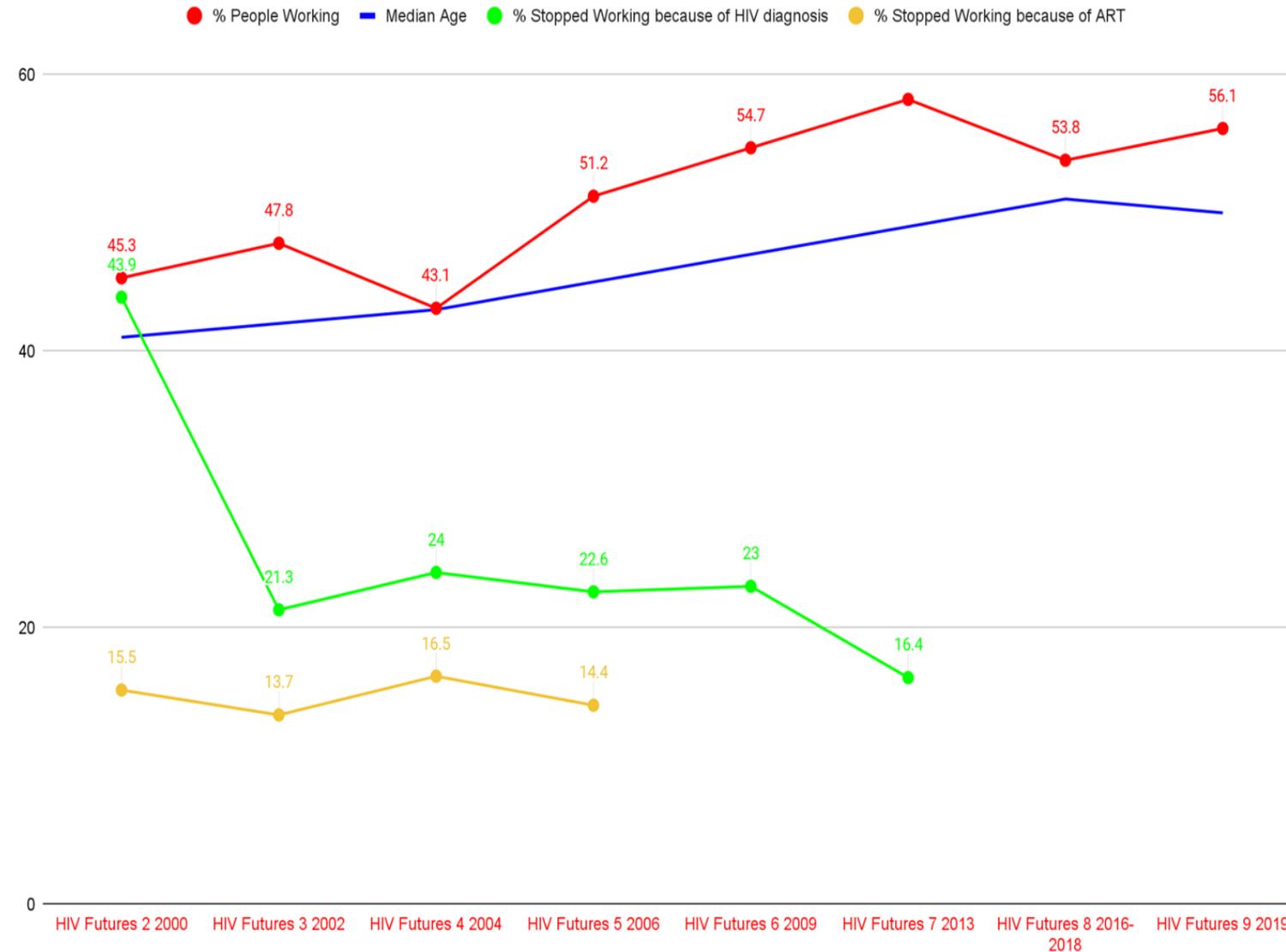
51.8% people reported
unwanted disclosure.

- Unwanted disclosure appears to hover on the 50% mark from **HIV Futures 2 2000** through to **HIV Futures 7 2013**. With no mention of it in **HIV Futures 8 2016** or **HIV Futures 9 2019**. Nevertheless, unwanted disclosure appears to be an issue that is consistent and prevalent.
- (In **HIV Futures 2 2000** **59.9%** people reported unwanted disclosure. **3 2002** **52%**. **4 2004** **55%**. **6 2009** **51.4%**. **7 2013** **52.8%**. In **8 2016** & **9 2019** nil).

HIV Futures 6 2009 Making positive lives count

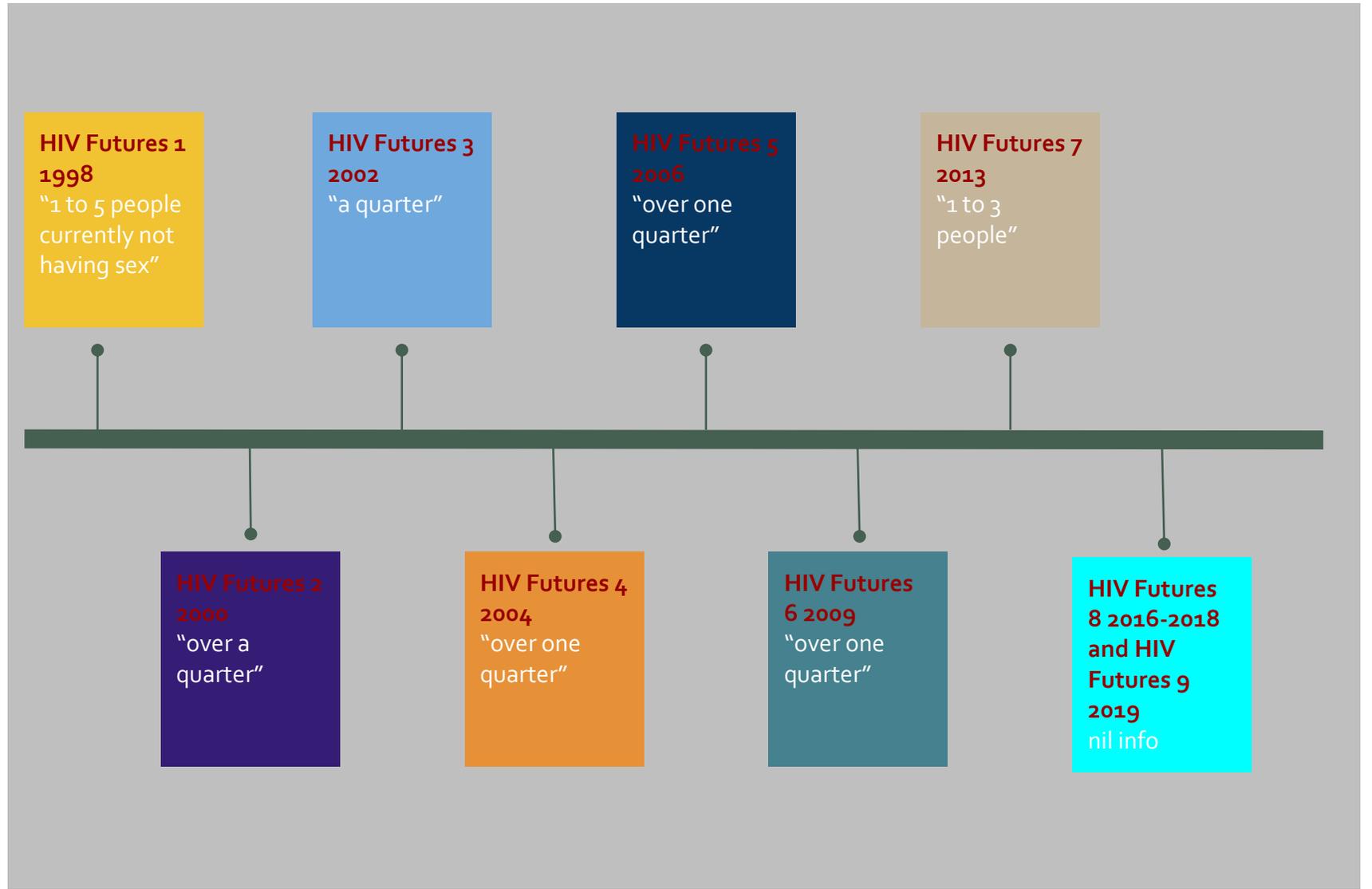
54.7% people reported
having a full-time, or part-
time, or casual
employment.

Employment



HIV Futures 7 2013 The Health and Wellbeing of HIV Positive People in Australia

1 to 4 people reported that
they currently were not
having sex.



Women living with HIV

Women living with HIV was first discussed in-depth

in HIV Futures 8 2016-2018, and the scope of discussion was expanded in HIV Futures 9 2019.

HIV Futures 8 & 9 captured prevalent discourses such as:

financial stress, poverty, difficulty in gaining a romantic relationships due to stigma, parental experience including breastfeeding, housing instability, unwanted sexual activity, violence and poor mental health.



FURTHER AND CONTINUOUS IN-DEPTH RESEARCH IS IMPORTANT!

The data thus far has been a crucial tool informing practice

in the fields of research, policy, advocacy and direct service delivery.

Holistically, the Futures study captured data

around HIV acquisition and diagnosis, comprehensive demographic characteristics, quality of life, health conditions, treatment and clinical care, and sex and relationships.

HIV Futures 9 2019 Quality of life among people living with HIV in Australia

Aboriginal and Torres Strait
Islander Peoples' demographic
characteristics were
discussed further.

Survey / Year of Survey	Sample Population: Aboriginal and Torres Strait Islander Peoples	Sample Population: Aboriginal and Torres Strait Islander Peoples (in n)
HIV Futures 1 / 1998	3% of total respondents	N/A
HIV Futures 2 / 2000	2.4%	22
HIV Futures 3 / 2002	1.7%	15
HIV Futures 4 / 2004	2.9%	31
HIV Futures 5 / 2006	1.9%	18
HIV Futures 6 / 2009	2.3%	25
HIV Futures 7 / 2013	2.1%	22
HIV Futures 8 / 2016-2018	2.3%	21
HIV Futures 9 / 2019	1.5%	13

Research barriers:

- HIV Futures (9 2019) acknowledged for the first time the number of sample is very small and that there needs to be more resources in research to better understand Aboriginal and Torres Strait Islander people's needs.
- Reading and writing literacy particularly for those who live in remote areas are a challenge.
- Services are lacking cultural responsiveness.
- Disclosure safety deters people from participating in research.

Where to now?

I would like to advocate for cognitive health to be included in the HIV Futures study. What I want to know now and into the future is:

- We know that cognitive health is important for a good quality of life. My understanding is that cognitive decline may be linked to long term side effects of medication, or traumatic events leading up to HIV diagnosis and post diagnosis through to different stages of lifespan, or the virus itself.
- We know that the risk for cognitive changes in PLHIV is double compared to non PLHIV. Twice as likely.
- So, I want to gauge the extent of the micro, meso and exo impact of cognitive issues in a person's ecology.
- And, I want to know what sort of external stimuli can be considered as harmful input into people's systems.
- Also, I am interested to find out how do people cope, how do people navigate day to day living - sex, sexuality, relationship, sensuality, intimacy, psychosocial milestones, work, accommodation, education. How do you support people with so much needs that are complex and who are occupying multiple vulnerable intersectionalities.