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A HIV diagnosis and treatment cascade for Aboriginal and Torres Strait Islander peoples of Australia

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ABSTRACT

Aboriginal and Torres Strait Islander (hereafter Aboriginal) people are a priority population for HIV care in Australia; however, no HIV cascade exists for this population. We developed annual HIV cascades for 2010–2017 specific to Aboriginal peoples. By 2017, an estimated 595 Aboriginal people were living with HIV (PLWH); however, 14% remained undiagnosed. Cascade steps below global targets were: PLWH aware of their diagnosis (86%), and retention in care (81% of those who had received any care in previous two years in a sentinel network of clinics). For people retained in care, treatment outcomes surpassed global targets (92% receiving treatment, 93% viral suppression). Increases occurred across all HIV cascade steps over time; however, the least improvement was for retention in care, while the greatest improvement was achieving viral suppression. The HIV cascade for Aboriginal peoples highlights both gaps and strengths in the Australian HIV care system, and importantly highlights where potential interventions may be required to achieve the global UNAIDS targets.

Introduction

Diagnosis, care and treatment cascades are used to monitor and improve healthcare outcomes. For people living with HIV (PLWH), the HIV cascade is used at a population level to identify strengths and gaps in HIV diagnosis, care and treatment delivery (Jose et al., 2018; Kay et al., 2016; Medland et al., 2015), including for monitoring the UNAIDS global targets to end AIDS (UNAIDS, 2014). These global targets proposed by UNAIDS in 2014 aim to achieve "90-90-90" by 2020 (UNAIDS, 2017). That is, 90% of people living with HIV know their HIV status, of these 90% are receiving HIV treatment, and of these 90% are achieving viral suppression status (UNAIDS, 2017). While many countries have fallen short of these targets (Marsh et al., 2019), with this shortfall due to entrenched inequalities (UNAIDS, 2020), the UNAIDS has proposed even more ambitious "95-95-95" targets by 2030 (UNAIDS, 2014).

Globally, Indigenous peoples account for 5% of the world's population (World Bank, 2019) and are diverse, with more than 5000 different cultural groups across 70 countries, mostly living in remote or isolated areas. Due to ongoing oppression and discrimination, Indigenous peoples continue to be disproportionately affected by

HIV infection (IIWGHA, 2018; UNAIDS, 2018). Recently, an extensive systematic review of the HIV Cascade for Indigenous peoples of Australia, Canada, New Zealand and USA reported significant gaps (Jongbloed et al., 2019). Very few papers included in the review provided data for the treatment and care components of the cascade, the longitudinal data was limited, and not one of 93 papers gave a complete HIV Cascade for an Indigenous population (Jongbloed et al., 2019).

Within Australia, Indigenous peoples comprise two distinct groups; Aboriginal people and Torres Strait Islander people (hereafter collectively referenced as Aboriginal peoples). These people are recognised as the First Australians and custodians of the oldest living continuous culture (Malaspinas et al., 2016; Nunn & Reid, 2015). Representing around 3% of the total Australian population (ABS, 2018), they and are a heterogenous, young, and disadvantaged population, as measured by a range of social determinants of health including poorer outcomes in education, lower income and employment levels, and reduced access to healthcare (ABS, 2018). The population faces significant challenges resulting from ongoing impacts of colonisation, including intergenerational trauma, discrimination, stigma and racism, that continue to influence their

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overall health profile as well as HIV risk (Marmot, 2005; Paradies, 2016).

National HIV surveillance has been enumerated for Aboriginal people since 1992, although retrospective audits show HIV cases in Aboriginal peoples have occurred since 1984 (Kirby Institute, 2018b). For the first 30 years of the HIV epidemic in Australia, similar rates of diagnosis occurred among Aboriginal and non-Indigenous Australians (Kirby Institute, 2018b). However, more recently there has been a clear divergence in HIV diagnosis rates: increasing in the Aboriginal population while concurrently decreasing in the non-Indigenous population (Kirby Institute, 2018b). As such, HIV diagnosis rates among Aboriginal people are now twice the rate of non-Indigenous Australians (Kirby Institute, 2018b; Ward et al., 2018). Reasons for this widening gap potentially include the later uptake of HIV biomedical prevention initiatives, as well as a shortfall in tailored responses for the epidemiological profile of HIV in the Aboriginal population, including efficacious strategies for women, heterosexual people, and people who inject drugs (Kirby Institute, 2018b).

While an HIV cascade exists for the overall Australian population (Kirby Institute, 2018b), which is already near achieving the newly revised "95-95-95" UNAIDS targets, it masks outcomes for key populations, including Aboriginal peoples. Given the widening gap in HIV diagnosis between Aboriginal and non-Indigenous people in Australia, the global shift towards "95-95-95" targets, and the lack of a complete HIV cascade for any Indigenous population globally, it is timely to develop a cascade to better understand where gaps exist in the HIV diagnosis, care and treatment pathway for Aboriginal peoples. Furthermore, it is important to understand how the HIV cascade has changed over time to further direct targeted strategies. Here, we present the first HIV cascade, including changes over time, for Aboriginal peoples of Australia.

Methods

Separate HIV cascades were developed for each year during 2010–2017 for Aboriginal peoples, using three data sources: (i) the National HIV Registry for diagnosed cases (Kirby Institute, 2019b); (ii) the outcomes of the European Center for Disease Control (ECDC) HIV modelling tool (ECDC, 2017) to estimate the proportion of PLWH but not yet diagnosed; and (iii) de-identified patient data from the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance of Sexually Transmissible Infections and Blood-borne Viruses (ACCESS) (Kirby Institute, 2019a) for received any care and retention in care, as well as treatment

uptake and outcomes. The diagnosis components were calculated separately to the care and treatment components and then compiled into a complete cascade. A description of the specific methods used for each step of the cascade is described below.

Data sources

Diagnosed cases

Permission was sought from the National Blood-Borne Virus and Sexually Transmissible Infections Surveillance Sub-committee to access National HIV Registry data for the period 1992–2017. The National HIV Registry contains information on all people diagnosed with HIV in Australia since 1984, including date of diagnosis, age, gender, CD4 count, Aboriginal and/or Torres Strait Islander status, and possible modes of HIV exposure as reported by the diagnosing clinician (Kirby Institute, 2018b). The completeness of these variables is high, with Aboriginal and/or Torres Strait Islander status routinely collected for Aboriginal peoples since 1992, with the proportion of unknown status varying between 0.5% and 1.4% (Kirby Institute, 2018b). Retrospective data audits ensure the completeness of the data, with all data checked to ensure no duplicate data are included.

Undiagnosed cases

Data for estimating the total number of Aboriginal PLWH but undiagnosed was calculated using the ECDC HIV Modelling Tool(ECDC, 2017) using a multi-state back-calculation model of data from the National HIV Registry, including CD4 count at diagnosis and standardised mortality rates among Aboriginal peoples. A total of 100 simulations were run to obtain the best estimate with bootstrapped 95% confidence intervals (95% CI), which were used as the range for all output (Kirby Institute, 2018a).

To account for the proportion of people who died after an HIV diagnosis, all-cause death rates for Aboriginal PLWH were estimated by adjusting the overall death rate, using methodology based on a data linkage study (Nakhaee et al., 2009), and a large national cohort study (McManus et al., 2012), to reflect the higher mortality in the Aboriginal population compared to the non-Indigenous population (ABS, 2019). We assumed no Aboriginal PLWH moved overseas during the study period.

Health care and treatment data

The ACCESS data is derived from a national sentinel surveillance network comprising over 120 urban, regional and remote health services and pathology

laboratories across all Australian jurisdictions (Callander et al., 2018; Kirby Institute, 2019a). The network includes nearly all publicly funded sexual health clinics in Australia, plus a selection of general practices and hospitals with a high case load of PLWH. Data was extracted from ACCESS for the period 2010–2017. Details of the ACCESS system are described elsewhere (Callander et al., 2018).

Calculating care and treatment components In the cascade

From ACCESS, any PLWH who had a record of health-care in the past two years were defined to have "received any care". A PLWH was then defined to be "retained in care" if they had received HIV-related care at least once in the past 12 months. The proportion of people on ART was calculated as people who had ART prescribed or evidence of viral suppression of less than 200 copies/mL in the previous 12 months. The proportion of PLWH achieving viral suppression was those who had a viral load of less than 200 copies/mL within the past 12 months. For completeness we included an additional cascade step titled "viral load testing" to measure the proportion of PLWH who had a viral load test in the previous 12 months, with an evaluation of viral suppression restricted to these people with a viral load result available.

Data analysis

Using the created cohort of PLWH, all data were combined to develop the HIV cascade annually during 2010–2017. The proportion of people within each step was calculated as a proportion of those people in the preceding cascade step. The ECDC modelling tool, freely available online (ECDC, 2017), produces output in Microsoft Excel (Microsoft Corporation, Redmond, US). Reproducible code and analysis documentation are available online (Gray, 2017), with cleaned input data and the ECDC tool raw result files available on request. Data are reported as proportions and presented as graphs, including changes over time. Analyses were produced using R software (Version 3.3.2), a programming language for statistical computing (The R Project, 2017).

Results

The resultant HIV Cascade is presented in Figure 1. At the end of 2017, we estimated 595 Aboriginal PLWH in Australia (range: 523–683 people). Of these, an estimated 84 people (range: 50–151, 14.2%) were undiagnosed. In the sentinel network of clinics, 394

Aboriginal people had a record of care in the preceding two years with 318 (80.7%) retained in care. Of these, 293 (92.1%) were recorded as receiving ART in the past 12 months with only 113 (38.6%) having viral load testing results available in the ACCESS database. Among those Aboriginal people who had received a viral load test, only 105 (92.9%) had a record of HIV viral suppression.

HIV cascade changes over time

Over time, the estimated number of Aboriginal PLWH steadily rose from 385 people in 2010–595 people in 2017 (Figure 2). During the same period, the estimated proportion of undiagnosed PLWH decreased from 20% to 14%. Both the care and treatment cascade steps have steadily increased with the number of PLWH having received any care in the preceding two years increasing from 257 people in 2010–394 people in 2017 and the percentage of those retained in care increasing from 74.3% to 80.7% over the same period. Viral load testing among people on ART remained relatively low throughout the study period (range: 34.9% to 44.2%); the proportion in 2017 was 38.6%. Of people with a record of viral load testing done within the previous year, the proportion achieving viral suppression increased from 62% in 2010 to 92% in 2017.

Discussion

For the first time, we have shown where strengths and gaps exist in the UNAIDS targets for Aboriginal peoples in Australia. This is the first complete HIV Cascade for an Indigenous population internationally (Jongbloed et al., 2019), and the first to include longitudinal data demonstrating changes over time. When matched with the UNAIDS "90-90-90" global targets for 2020, some aspects of the cascade met these thresholds (on treatment and viral suppression), while others did not (diagnosed HIV and retention in care). While none yet meet the UNAIDS "95-95-95" targets, we have shown there were signs of moving toward these during the study period.

We estimated in 2017 nearly 14% of HIV cases among Aboriginal peoples remained undiagnosed. While a reduction from 20% in 2010, much work remains to be done as the proportion of Aboriginal PLWH who are not aware of their diagnosis remains nearly double their non-Indigenous counterparts. Local strategies are required to improve testing rates, especially among those most marginalised, including people who inject drugs, and gay, bisexual and other men who have sex with men. Strategies to increase
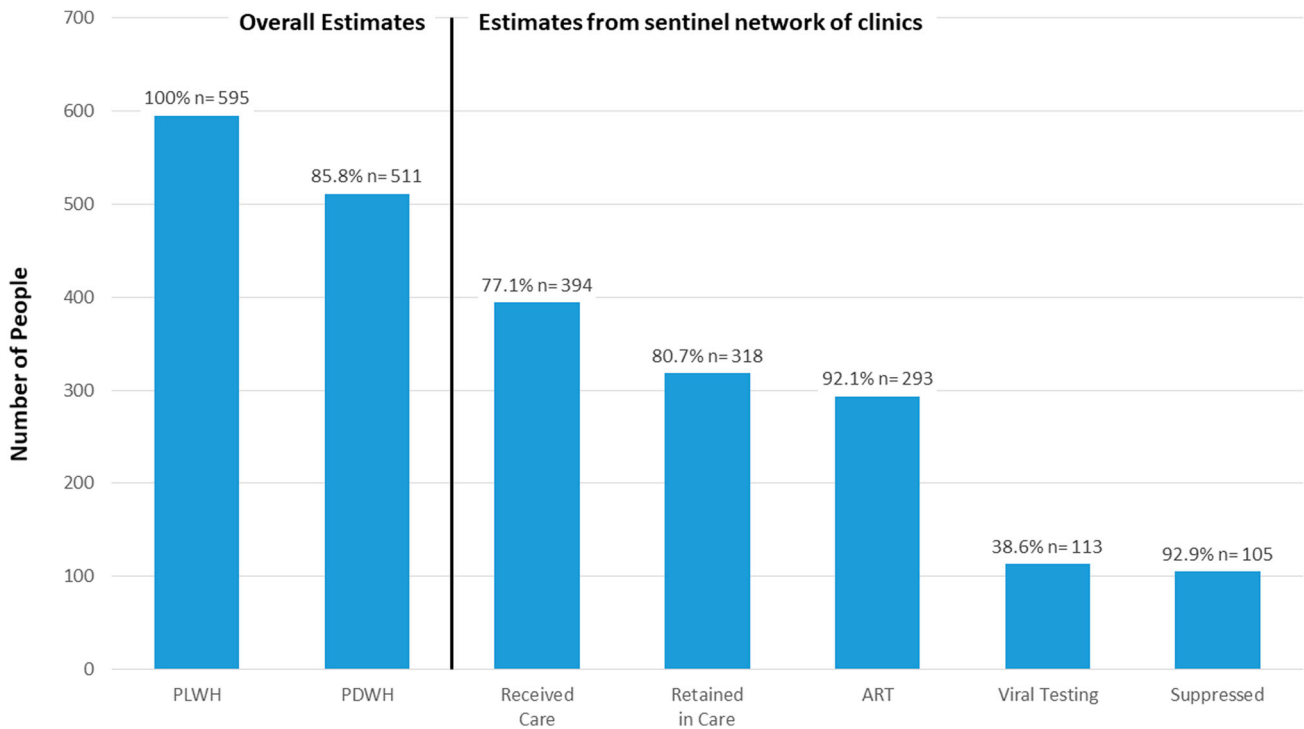
Figure 1. Changes over time for each HIV Cascade step, 2010–2017, for Aboriginal People living with HIV. PLWH – People living with HIV, PDWH – People diagnosed with HIV, ART – antiretroviral therapy.

HIV testing among Aboriginal people include point-of-care testing (J. Ward et al., 2012) in locations where HIV has been detected previously and among high-risk populations. Similarly, targeted health promotion campaigns (NACCHO, 2019) and optimising opportunistic screening (RACP, 2019) are suitable interventions, especially in communities where the prevalence of other STIs is extremely high and where testing rates
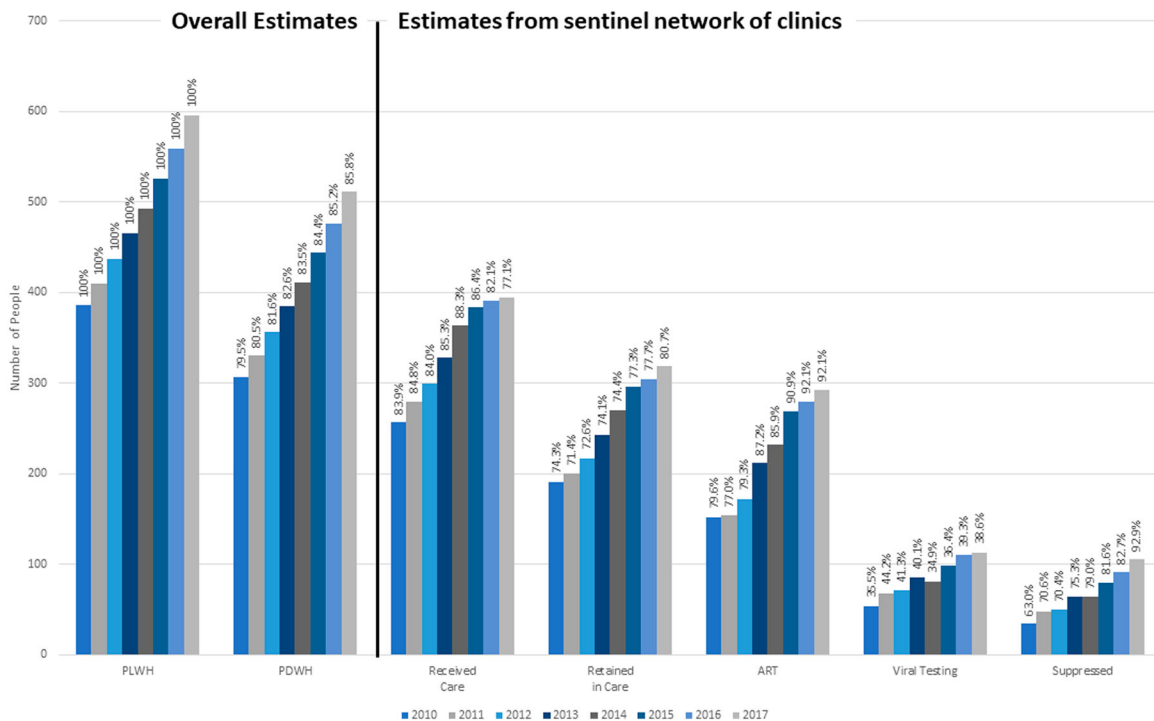

Figure 2. HIV Cascade for Aboriginal and Torres Strait Islander People living with HIV, Australia, 2017.

remain low even after a positive STI diagnosis (J. Ward et al., 2018).

Improving engagement and retention in care should be a key focus in ending HIV among Aboriginal peoples in Australia; both steps fall short of the UNAIDS targets. Research shows for Indigenous peoples worldwide there are key determinants influencing their engagement in HIV diagnosis and treatment (Jongbloed et al., 2019). Factors promoting engagement in the HIV care are mindfulness of Indigenous culture and identity, including strength and resilience of Indigenous peoples, and availability of social support systems (Jongbloed et al., 2019). In contrast, engagement with the health system is hindered by historical intergenerational trauma, by stigma and discrimination, and by the intersection of health concerns and social stigma that often impacts on Indigenous peoples (Jongbloed et al., 2019). In Australia, one local solution was to establish multidisciplinary care teams to travel to distant communities, conduct comprehensive contact tracing, and follow-up people diagnosed with HIV (Queensland Health, 2017). The program was built on a foundation of trust and rapport between the health services and the local community, which was important as ongoing mistrust of the health system contributes to low engagement and retention within healthcare among Aboriginal peoples, thus impacting their health outcomes (Negin et al., 2015). While such targeted responses require substantial resources, they have been shown to improve the retention of Aboriginal people in HIV care (Dempsey et al., 2015).

A positive aspect of our research was to show that once retained in care Aboriginal PLWH do as well as non-Indigenous people in relation to treatment uptake and achieving viral suppression. We show the proportion of people who received treatment and achieved viral suppression increased significantly from 2010 to 2017; these were the largest improvements within the HIV cascade. Previous research showed viral load suppression is impacted by a delay in HIV detection and commencement of treatment (Ssekalembe et al., 2020), as well as suboptimal treatment adherence due to socioeconomic, cultural, and social factors (Siefried et al., 2017). Given this, as the proportion of people retained in care and receiving treatment increase, so too we expect the proportion of people achieving viral suppression to increase. However, the increase in viral suppression was larger than expected, and similar improvements have been seen in USA (Nance et al., 2018). These findings highlight the importance of increased early detection and supported engagement with healthcare in achieving viral suppression for PLWH.

Originally, UNAIDS proposed global "90-90-90" targets be reached by 2020 (UNAIDS, 2017), with more ambitious "95-95-95" targets to be achieved globally by 2030 (UNAIDS, 2017). However, Australian HIV agencies are even more ambitious, wanting to achieve "95-95-95" by 2022 (Australian Government, 2018). With the "90-90-90" goals yet to be achieved, it raises questions if "95-95-95" targets will be met by 2022 in Australia. Despite the UNAIDS championing the targets and significant gains being made, the momentum towards reaching the targets has slowed (UNAIDS, 2019). UNAIDS recognises gaps in service delivery are due to entrenched inequalities, particularly for Indigenous peoples who experience exclusion from health systems or find these systems unavailable or inappropriate for their care (UNAIDS, 2020).

A strength of this paper is the aggregation of data using multiple data sources. This approach has produced for the first time a complete HIV Cascade for Aboriginal peoples, including every step from diagnosis to HIV suppression, which has not previously been published for any Indigenous population. Another strength was our access to historical data, which allowed us to demonstrate how the HIV Cascade has changed over time. Together these data provide crucial insight where gaps remain in the diagnosis and treatment steps of the cascade.

Conversely, our estimations have limitations. Firstly, the proportion of people who achieved viral suppression could only be calculated for those people who had viral load testing recorded in the ACCESS database; only 38.6% of people receiving ART had viral load testing. Testing rates are likely much higher than our results suggest, as viral load testing is a clinical standard component of HIV care. As such, a potential explanation is a lack of documentation of requests for testing and test results, with the latter caused when results are provided in hardcopy form and not manually entered into electronic records. However, this is unlikely to account for the entirety of the low viral load testing numbers as such, testing rates are clearly suboptimal. Secondly, our estimations use ACCESS Network data, which covers 120 urban and regional clinics incorporating most services prescribing HIV medicines nationally. While other local data have reported similar findings to our study (Jongbloed et al., 2019), and despite being comprehensive, the ACCESS network is not exhaustive. There are clinics outside the network providing HIV care, most notably Aboriginal Community Controlled Health HIV Services. Thus, care would have been provided at clinics outside the ACCESS network, resulting in an underestimation of PLWH receiving and retained in care. Data from other sources could address this gap,

including data from ATLAS, an established national sexually transmitted disease and blood-borne virus surveillance network specific to Aboriginal and Torres Strait Islander peoples, which collates data from clinical hubs located across regional and remote Australia (Bradley et al., 2019). Even if gaps contribute to an underestimation, we do not expect this would impact on the changes over time. Finally, to be included in the ACCESS dataset, PLWH need to have visited a service in the past two years, thus people who are disengaged from care for a long timeframe would be excluded, over-estimating the ongoing retention in care step, potentially more so for Aboriginal people than non-Indigenous people.

One method to address these potential selection biases would be to link the National HIV Registry data with the Medicare and Pharmaceutical Benefits Schemes data, thus capturing all reimbursed health care visits and HIV treatments dispensed among Medicare eligible Australians. In addition, limitations in the use of the ECDC model to produce estimates of undiagnosed HIV cases for the most recent years were evidenced by the variations in the estimates for 2016, 2017 and 2018 which were impacted by fluctuations in the number of HIV notifications.

Conclusion

Ward et al. (2018) highlighted the intersection between the social and cultural determinants of health, and how these impact HIV risk for Aboriginal peoples, need to be better recognised. Only in understanding and addressing these issues can improvements be made to better engage Aboriginal PLWH in HIV care. Our findings clearly highlight the current gaps in HIV care delivery and provide a basis for ongoing monitoring of these gaps into the future. This HIV Cascade for the Aboriginal population of Australia provides learnings to inform the development of HIV Cascade for Indigenous populations elsewhere. Furthermore, the findings are an important foundation for policy development and strategic implementation of culturally appropriate and timely interventions to close gaps in HIV care.

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Data availability statement

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