



# How can we set targets without the evidence? Achieving recognition for all women living with HIV in Australia

By **Alison Boughey, Autumn Pierce** and **Michelle Wesley**

On the first day of the 20th International AIDS Conference in Melbourne in July 2014, the Council of Australian Governments (COAG) Health Council released the *AIDS 2014 Legacy Statement*, a statement agreed to by all of Australia's Health Ministers pledging to work towards the virtual elimination of HIV transmission in Australia by the end of 2020. The *Seventh National HIV Strategy 2014–2017* outlines how Australia intends to meet this ambitious target. It identifies eight priority populations to which Australia's HIV response will be targeted in order to maximise its impact and sustainability.<sup>1</sup>

While women are a subgroup of seven of these eight priority populations named in the Strategy, they are not identified as a priority population in their own right. This makes planning and implementing a tailored, targeted response to women challenging. The absence of women as a distinct priority group on the national

HIV agenda will hinder efforts to achieve an AIDS-free generation at a time of unprecedented opportunity.

Although the National HIV Strategy is developed in response to the latest data about HIV in Australia, the methods of data collection that inform key publications dealing with the epidemiology of HIV in Australia do not include an accurate representation of women's experiences of living with HIV in this country.

Take, for example, the HIV Futures Survey – Australia's national survey about health, treatments, work and the financial situation of people living with HIV. The Futures survey is highly regarded as one of the most comprehensive pictures of life with HIV in Australia; however, when looking at the most recent survey data (HIV Futures Seven, 2013), the sample size of HIV-positive women who participated does not reflect the percentage of women living with HIV

in Australia. Out of the 1058 survey participants in HIV Futures Seven, only 6.7 percent were women<sup>2</sup>, whereas the percentage of women with HIV within Australia's overall population of people with HIV is estimated to be around 10 percent<sup>3</sup>. Clearly, a more targeted recruiting approach is required to increase the number of women respondents and improve the applicability of the findings.

It is also essential that gender-segregated analysis and reporting of the data is undertaken. In Futures Seven, aside from the demographic summary, reported data is only segregated by gender in the sections relating to relationships and children. An absence of analysis around the gender-related disparities in the HIV experience that extend beyond sexual and reproductive issues has significant consequences for organisations supporting women with HIV. Further evidence to inform an understanding of the non-sexual, social aspects of the lives of women

with HIV would be extremely helpful. This could be derived by including questions regarding the influence of personal characteristics and cultural context on respondents' sense of identity, sources of social support and gaps in the availability of current support.

The Kirby Institute 2014 Annual HIV Surveillance Report does provide useful gender-specific data relating to women and HIV transmission via heterosexual contact, however again, the data presented in the body of the report are focused on priority populations, as per the National Strategy. This means that women are only mentioned if they are also members of a priority population, such as sex workers, people who inject drugs and/or members of Aboriginal or Torres Strait Islander communities. The absence of 'women' as a subcategory in surveillance reports, and the limited capacity of surveillance data in general to provide contextual details about the lives and needs of women living with HIV, means that these reports offer little to meaningfully inform service provision for women.

The fact that these two highly-regarded publications are key documents referred to by policy makers in developing the country's HIV response may go some way to explaining why the needs of women are not being prioritised as a part of Australia's HIV response. A priority population should be defined not only by the raw numbers of people affected, but by the service delivery challenges the population presents. From the limited data that we do have, we know that women have an entirely different experience of living with HIV than men and face unique barriers to prevention and treatment. Known differences in modes of transmission, biological susceptibility, geographical accessibility, socioeconomic status, testing patterns, service use, health seeking behaviours, perceptions of risk and attitudes towards treatment all provide a robust starting point for service provision, but more sound, reliable information is desperately needed to inform strategic decision making.<sup>4,5</sup>

On an international scale, women and girls are the number one priority in the response to HIV. In 2010, Michel Sidibé, Executive Director of UNAIDS reported on progress to date and said, 'This epidemic unfortunately remains an

epidemic of women.'<sup>6</sup> More recently, in her address at the 2014 AIDS Conference in Melbourne in July 2014, Dr Lydia Mungherera said, 'I think the face of the pandemic is a female face.'<sup>7</sup>

The epidemiology of the virus differs in every country, but some of the same factors that put women at risk in Uganda or Cambodia are putting women at risk in Australia. The difference is that in international settings, resources have been allocated to identify gender-related disparities as a result of biological, structural and cultural factors and have been more fully integrated into the international HIV response.

More detailed data collection, analysis and reporting would assist organisations supporting women with HIV, such as Positive Women Victoria, to improve service delivery and efficacy and provide a stronger foundation for evidence-based advocacy. Data that accurately supports the legitimacy of women to claim priority population status would also go some way to helping combat the social stigmatisation experienced by many women.

For many women, stigma associated with their HIV status is experienced differently to the stigma men experience and yet is not often differentiated from that of men. Women must cope with what Reidpath and Chan referred to as 'layers' of stigma or multi-dimensional stigma.<sup>8</sup> In addition to having a feared, contagious disease, women are also frequently ascribed the label of 'character deviance'. Their perceived role as vectors of disease to their unborn children adds another layer of vulnerability and judgement. The complex networks of relationships in women's lives and the structures which shape them must be considered when developing policies and services in the Australian context.

Optimistically, promising changes are underway. For the first time, the HIV Futures team, which is scheduled to commence data collection for the Futures 8 survey in the second half of 2015, has designed a parallel data-collection approach targeted at women. This will enable examination of issues specific to women with HIV and, it is hoped, produce gender-segregated HIV data that will allow services to more appropriately target their offerings to women's needs. Positive Women Victoria, as the only community-based organisation specifically

funded to support women living with HIV in Australia, will continue to support the efforts of researchers who endeavour to accurately capture the experiences of women living with HIV.

In addition, Positive Women is currently providing input into the work being undertaken by Victoria's Department of Health and Human Services to support the development of key strategic priorities and actions that will enable Victoria to achieve the Legacy Statement goals. Importantly, we will also be working towards the recognition of women as a priority population in the next National HIV Strategy. This is essential to create an enabling environment where women of all backgrounds, cultures, ages and experiences feel confident about accessing HIV testing, prevention and treatment services.

## References

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