

Challenges for research in improving the HIV response for culturally and linguistically diverse communities

By Jennifer Power and Jen Johnson

Introduction

In recent years Australia has seen a significant reduction in new HIV diagnoses, between 2014 and 2018 the number of HIV notifications reduced by 23% [1]. These reductions have been driven by new approaches to HIV prevention centred on diversifying HIV testing options, treatment as prevention (TasP), pre-exposure prophylaxis (PrEP) and ongoing campaigns to support PrEP uptake among gay and bisexual men. However, the Australian response to HIV is increasingly uneven, with some populations not receiving the full benefit of these new prevention options. While the rate of HIV notifications among Australia-born gay and bisexual men has decreased and has been stable among Australian born heterosexual people between 2008 and 2017, higher notification rates were evident among people born in Southeast Asia, the Americas and Sub-Saharan Africa [1]. A recent study also showed that, among people diagnosed with HIV, people born in South East Asia or sub-Saharan Africa were more likely to be diagnosed late than Australian-born people. They were also less likely to move quickly into care or access services to commence treatment. People ineligible for government subsidised healthcare (Medicare) were particularly affected [2].

People who were born in high HIV prevalence countries, people who travel to these countries, and their partners are listed as priority populations in the Eighth Australian National HIV Strategy 2018-2022 [3]. The HIV sector response is working to adapt existing systems to provide culturally appropriate and inclusive programs and services for people from a range of culturally diverse communities and backgrounds. There is currently a gap in research to understand the needs of people from culturally and linguistically diverse communities with respect to HIV testing, prevention strategies and support needs for people living with HIV. This gap is particularly notable given Australia has a long history of producing world leading, high quality social research relating to HIV and community-based prevention and support.

A history of HIV social research

From the 1990s, the Australian government led the way internationally in developing a model of funding for interdisciplinary HIV research. Four HIV research centres were funded, two focusing on clinical and epidemiological research and two specifically on social and behavioural research. The research produced by these research centres has

been internationally significant because of the innovative ways in which it connected public health and epidemiology with social science and the humanities – joining the dots between culture, identity, sex, sexuality, medicine and disease prevention.

Public health and health promotion research have traditionally been underpinned by assumptions that the key to improving health outcomes lies in influencing the knowledge, attitudes, behaviours and choices of individuals. Research methods often involve large-scale social surveys to identify whether a particular set of actions or beliefs increase a person's vulnerability to ill health. Much of the early HIV research followed this pattern, linking factors such as the number of sex partners a person has to their risk of acquiring HIV [4].

From the late 1980s onwards, HIV social research began to bring culture and politics into the field of public health. Assessing HIV 'risk' or making sense of attitudes toward safe sex were framed as studies of cultural and community processes rather than studies of individual psychology, knowledge and behaviours [5]. Researchers looked at the community and cultural networks of gay and bisexual men and the ways

these shaped sexual practices and safe sex ‘norms’. They also began to look at the politics of marginalisation and discrimination and link these to sexual practices and HIV ‘risk’. There were many factors influencing this shift in approaches to research. In part, it was the realisation that the global pandemic of HIV was taking different forms in different settings, and it simply didn’t make sense to assume the same set of factors shaped vulnerability to HIV in different jurisdictions and contexts. As Richard Parker [4] has written:

[On] the basis of both research findings and practical experience around the world, it had become clear that a far more complex set of social, structural, and cultural factors mediate the structure of risk in every population group, and that the dynamics of individual psychology cannot be expected to fully explain, let alone produce, changes in sexual conduct without taking these broader issues into account (page 165).

In addition, in the early 1990s, humanities and social science research was increasingly influenced by feminist methodologies and queer theory, each of which applied a cultural lens to the study of gender and human sexuality. In the context of HIV prevention work, these approaches led researchers to explore the ways in which structural and cultural factors produce people’s sense of themselves as a sexual being – how decisions about sex and safe sex occur within a pre-existing set of cultural meanings that shape and define human action [4]. This epistemological framework encouraged sociological and anthropological methodologies, with an emphasis on qualitative studies – interviews, participant observation, and cultural analysis of texts and media.

While the need to consider structural and cultural influences in HIV prevention research may seem pedestrian today, at the time it was a radical departure from traditional public health approaches to research. The extent to which HIV research worked alongside affected communities was also a unique approach to a public health problem (in the 1990s and still somewhat today). The partnership-model that has defined the Australian HIV response whereby

government, community, medical professions, researchers and people living with HIV have worked collaboratively to deliver the HIV response has also facilitated meaningful working relationships between interdisciplinary researchers (clinical, epidemiological and social-science) and people from affected communities. People living with HIV and affected communities have participated in research as co-investigators, advisors, and consultants, challenging conventional approaches to academic research that privilege scientific and formal ‘expertise’ over lived experience and community knowledge [6].

Where does social research sit within the biomedicalisation of HIV?

In recent decades, improvements in HIV treatment, conclusive evidence that effective antiretroviral treatment prevents the sexual transmission of HIV, advances in rapid HIV testing options, and the increasing availability of PrEP have renewed the strategic approach to HIV prevention and care. These advances are reflected in the current Australian National HIV Strategy, which has set targets of 95% of PLHIV diagnosed, 95% on ART and 95% virally suppressed [3]. While HIV social research is still strong in Australia, there has been a shift in funding priorities toward largescale quantitative studies that aim to measure the extent to which we have met these targets – mapping population-level change to assess whether we have increased rates of diagnosis, PrEP use, or treatment uptake among PLHIV. Beyond assessment of the targets, a lot of recent research has also focused on implementation science and upscaling – asking how we ensure biomedical prevention can work on a larger scale for more people [6]. The importance of smaller studies that seek to make sense of community and cultural processes are increasingly afforded less value where the fundamental strategic priority is increasing uptake of biomedicines.

Biomedical advances have facilitated a significant reduction in HIV transmission among Australian-born gay and bisexual men in Australia, without an equivalent

reduction among people born overseas. While epidemiological research allows us to see these differences in transmission, we still have much to learn about how to address this disparity. We do not know enough about what will support increased HIV testing among people from migrant or refugee communities, or what the impact is of broader structural issues or pressures facing many people from these communities, such as concerns about housing or financial security, racism or lack of culturally appropriate health services. Further, we still have some way to go to understanding experiences of HIV stigma in diverse communities. We also have only limited information about the needs and lived experiences of people living with HIV from migrant or refugee backgrounds. The gaps in the biomedically driven aspects of the HIV response reveal the extent to which HIV continues to be a ‘profoundly social condition’ [7]. This reinforces the continuing need for research that seeks to make sense of the cultural and social dimensions of HIV testing, prevention and care, including willingness to adopt biomedical prevention. Large scale survey data can show why geographical proximity to an HIV testing facility may increase testing rates, but it cannot explain why a person from a refugee background may be less likely to present for testing than someone born in Australia. Understanding this requires a different type of knowledge – localised, community-based knowledge that is collected with the assumption that a person’s cultural and social location matters, and that this influences the ways they relate to – or are excluded by – HIV-prevention or care initiatives [6].

Challenges to building an evidence base about culturally and linguistically diverse community needs

There are many different migrant communities in Australia, however, population numbers in these communities are often small. Generally, research funding decisions are determined by the extent to which a study will have widescale applicability and national impact. Therefore, it is difficult to acquire funding for small

studies that aim to identify local, contextual factors.

To manage the 'problem' of small population sizes, and in an effort to include people from culturally diverse communities in large studies, researchers often group people together under banners such as 'overseas born' or culturally and linguistically diverse. The category 'overseas born' can be valuable for mapping HIV epidemiological patterns and, importantly, it enables us to utilise National HIV Surveillance data to monitor gaps in the Australian HIV response. However, this limits the meaningful application of knowledge about people who are 'overseas born' in the design of HIV prevention or service sector responses. There is too much diversity within this group for it to be meaningful as it includes people from many different regions of the world, countries and language groups that often have limited cultural or linguistic commonality. When you also consider factors such as gender, sexuality or age differences, we see even greater diversity. The experiences of a young heterosexual woman from Indonesia, for example, will likely be very different to those of an older bisexual man from Pakistan, a white gay man born in the UK, or an older heterosexual woman from South Sudan. Research that will meaningfully inform health promotion or service delivery needs to be more locally directed to identify the needs and experiences of particular communities and groups [8].

Investment to diversify the HIV research workforce and to build the capacity of the existing workforce to develop relationships with new communities is required [9]. Much of the Australian HIV research workforce, including many HIV social researchers, have been drawn to the HIV sector due to their cultural knowledge, experience and commitment to the health of gay men who were acutely affected by HIV during the AIDS Crisis, and continue to be the group most affected by HIV in Australia. This is part of what has ensured Australian HIV social research has been of such high quality. Studies were often designed and delivered by people with access to informal knowledge, shared sensibilities, networks and connections

that made it possible to produce community informed and engaged research. While research skills are transferrable, doing research with new communities takes significant investment of time and resources to build knowledge, relationships and trust, and to ensure that communities are meaningfully involved in identifying priorities and making sense of research findings. It would be unethical, and likely ineffective, for researchers to develop and implement studies without this investment to enable more intensive engagement with culturally diverse communities [8,9].

Conclusion

Improving the HIV response in Australia requires research that can guide the development of culturally appropriate responses to HIV in these communities. There are blind spots and gaps in our evidence base that could be addressed by investment in appropriately designed social research. This will be vital to achieving targets in the current National and state/territory HIV strategies.

References

1. Kirby Institute (2018). HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report. Sydney: Kirby Institute, UNSW.
2. Marukutira T, Gray RT, Douglass C, ElHayek C, Moreira C, Asselin J, et al. (2020) Gaps in the HIV diagnosis and care cascade for migrants in Australia, 2013–2017: A cross-sectional study. *PLoS Med* 17(3): e1003044. <https://doi.org/10.1371/journal.pmed.1003044>
3. Department of Health. (2018). Eighth national HIV strategy. Canberra: Commonwealth Government.
4. Parker, R. (2001). Sexuality, culture, and power in HIV/AIDS research. *Annual review of anthropology*, 30(1), 163-179.
5. Dowsett, G. W. (2009). Dangerous desires and post-queer HIV prevention: Rethinking community, incitement and intervention. *Social Theory & Health*, 7(3), 218-240.
6. Aggleton, P., & Parker, R. (2015). Moving beyond biomedicalization in the

HIV response: implications for community involvement and community leadership among men who have sex with men and transgender people. *American Journal of Public Health*, 105(8), 1552-1558.

7. Aggleton, P., & Kippax, S. (2014). Australia's HIV-prevention response: Introduction to the special issue. *AIDS Education and Prevention*, 26(3), 187-190.

8. Power, J., Le Gautier, R., Johnson, J., O'Keeffe, D., & Bourne, A. (2019). Overcoming barriers to effective delivery of care and support for people living with HIV from culturally and linguistically diverse communities in Australia. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University.

9. Le Gautier, R, Thorpe, R and Power, J (2018). A Study of HIV Management, Care & Support Needs among People from Migrant and Mobile Populations in Australia. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University.

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