

Normalising HIV testing in a changing epidemic

By Jen Johnson

The eighth *National HIV Strategy (2018-2022)* outlines the importance of improving the frequency, regularity and targeting of HIV testing across all priority populations as a means of decreasing rates of late diagnosis and eliminating HIV transmission.¹ Maintaining and enhancing the capacity of healthcare providers to discuss and normalise HIV testing across all key affected populations is vital to achieving this. This requires an expansion of health professionals' and community-based health workers' knowledge of indications for HIV testing.

HIV-related stigma not only affects people living with HIV, but also creates barriers to people seeking testing and other health services. The *National HIV Strategy* points to the essential role played by the health and community workforce in addressing and reducing stigma and discrimination in HIV testing, care, support and prevention services. It also calls for work that supports healthcare professionals to be well informed about the most effective ways to engage with and support priority populations.¹

So, what does expanding testing coverage and reducing stigma in healthcare settings look like in practice? Certainly, it means establishing more testing sites with flexible hours, including outreach programs. It also means increasing the availability of new HIV testing technologies such as rapid

point of care and self-testing. Most crucially, perhaps, it means supporting healthcare providers who don't routinely *think HIV* to sensitively initiate HIV testing conversations across all patient groups.

The BBV Sector Development Program at the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University recently conducted a qualitative study to better understand how best practice approaches in HIV testing discussion are defined in real-world testing settings. Data were collected from interviews and focus groups with clinical and community-based HIV testing providers, plus key informants from community-based, research, policy and workforce education settings (n=40).

This article provides an overview of the findings from the study and offers insights into how healthcare providers can approach and initiate HIV testing in a changing HIV landscape.

From pre-test counselling to normalising HIV testing

Pre-test counselling was a practice developed by HIV-affected communities in the early years of the HIV/AIDS epidemic – a time when HIV tests were inaccurate and there were no effective treatments. Pre-test counselling was a means of supporting people to think through the decision to test, to consider

the implications of a positive test result, and to explore behaviour change strategies to prevent acquisition of HIV.²⁻⁶ Most Australian jurisdictions introduced legislative requirements for pre- and post- HIV test counselling during this time.

Since then, improvements in HIV treatment and care have gradually resulted in the reframing of HIV from a largely fatal disease to a chronic manageable condition, and formal requirements for HIV testing have been removed. Despite this, in our consultations we were told that many healthcare providers still believe that a specialised process or approach is required to initiate HIV testing and they do not initiate testing as a result. Shifting this perception is a crucial part of expanding HIV testing across all affected populations. Healthcare providers do not need expert knowledge in HIV disease management or specialist skills in counselling and behaviour change to initiate testing.

Normalised HIV testing is the integration of HIV testing into general preventative health care. HIV testing will be normalised when all healthcare providers feel comfortable initiating testing as part of general health care, are able to provide basic HIV information in a non-judgmental manner and know when and where to refer.

HIV testing will be normalised in the general community when people accessing primary and community health services, regardless of their vulnerability to HIV, either expect to be asked about HIV testing or are comfortable and safe when it happens.

Workforce education initiatives are needed to support more providers to initiate testing conversations with more patients more often. These will be particularly important for general practitioners (GPs), especially those with limited experience with HIV diagnoses and limited connection to the HIV sector.

Stigma-sensitive practice

The concept of *stigma-sensitive practice* emerged from this study to describe specific and practical ways that healthcare providers can effectively initiate and normalise HIV testing. Stigma-sensitive practice involves the conscious use of basic communication and rapport-building skills to convey the practitioner's awareness that stigma exists and is exacerbated in healthcare settings, and that testing can be a stressful experience. It means creating environments where people feel safe and respected, and preserving privacy and confidentiality to the highest possible degree. It involves acknowledging and attending to any distress or support needs that may arise.

Stigma-sensitive communication uses neutral language that is free from judgement or suggestion that people are not taking responsibility for their health. For example, the use of open, reflective questioning when discussing risks (*What sort of HIV prevention strategies do you try to use?*) instead of routine closed questions (*How often do you have unsafe sex?*) can reduce the stigma and shame that people may experience.

From risk assessment to risk disclosure

Many people experience stigma and discomfort when healthcare providers undertake a risk history or risk assessment prior to HIV testing. This can deter people from seeking regular HIV testing. In this study, we found that

the risk assessment procedure can also be uncomfortable and difficult for healthcare providers, and may even deter some from initiating testing. Given this, another part of normalising HIV testing is minimising the use of invasive and confronting questions about personal risk practices.

It is not necessary for healthcare providers to ask direct questions about patient risk factors to proceed with HIV testing. Instead, test providers can specifically name the practices associated with transmission, for example unprotected condomless sex or sharing injecting equipment, and then encourage patient-led disclosure by asking if there are any questions or events they would like to discuss. When working cross-culturally, mentioning less stigmatised transmission routes such as unsterile medical or cosmetic procedures may help to de-emphasise transmission routes related to sexual and drug using practices. Conversations about risk need to be patient-led and sensitive to the patient's cultural and community context.

Providing information about risk factors in a stigma-sensitive manner supports people being tested to assess their own degree of HIV risk and prepare for a possible positive result. Many patients will not disclose any information about their personal risks, however, an absence of disclosure does not indicate an absence of risk.¹

If direct questions about risk practices for HIV are deemed appropriate in the testing context, it is important to use language that is inclusive of all genders and bodies, sexualities, and relationship types. Test providers should be comfortable with providing further information in a stigma-sensitive manner about each question they ask.

Expanding testing coverage in underserved communities

Recent biomedical advances in HIV treatment and prevention have resulted in rapid reductions in transmission among Australian-born gay, bisexual and other men who have sex with men, who are the main population affected by HIV in Australia. However, there are

many other populations affected by HIV who have not historically been centred within the Australian HIV response, and who have benefitted far less from these new technologies. This includes gay and bisexual men who are born overseas, Australian- and overseas-born heterosexual people, and people of Aboriginal and/or Torres Strait Islander background.

It is essential that testing approaches be tailored to the needs of priority populations and sub-populations, particularly where there is a need to improve early diagnosis. Late HIV diagnosis is associated with poor prognosis. Rates of late diagnosis are an important benchmark for testing coverage and are a broad indicator for how effectively the Australian HIV response is working across all key populations. 36% of new HIV diagnoses in Australia in 2017 were classified as late or advanced, representing a slight increase on previous years. Of these late diagnoses, 48% were among those who acquired HIV through heterosexual sex. Late diagnoses are more common among people born in high-prevalence countries (particularly South-East Asia and sub-Saharan Africa), Aboriginal and/or Torres Strait Islander people, and women.⁷

There has been a lack of both population-level and targeted HIV messaging for migrant and mobile populations, Aboriginal and Torres Strait Islander people, and heterosexual women and men. In these communities, historically considered to be communities at low risk of HIV, HIV stigma is much higher and HIV knowledge and health literacy is much lower.

Increasing testing rates in these communities will require a multi-pronged approach. The involvement of people living with HIV, and the meaningful engagement of leaders and representatives from underserved communities will be crucial to its success. Health promotion and other campaigns are needed to generate demand for testing within communities, and to develop the perception and belief that there is value for individuals and communities in seeking HIV testing.

New HIV diagnoses in Australia have declined by 23% in the last five years, and the number of new diagnoses in 2018 was the lowest since 2001.⁸ The decline in new HIV diagnoses has mainly occurred among gay, bisexual and other homosexually active men. This is powerful evidence that the Australian HIV response is effective, and that investment in programs targeting this key population needs to be sustained.

As new diagnoses attributable to sex between men decline, the number of new diagnoses in other key populations becomes proportionally larger. Significant investment is needed to expand service models and programs to ensure they adequately reach underserved populations. Resources urgently need to be allocated to fund the diversification of the HIV community and peer workforce so that it adequately reflects all communities affected by HIV.

Talking testing checklist

This study consolidated a checklist tool to support healthcare providers to initiate HIV testing. The tool offers a framework for gaining informed consent based on the principles that the person agrees to be tested, they understand the testing procedures and the reasons for testing, and they are able to assess the personal implications.

- Confidentiality and notification
- Testing history
- Health literacy and basic information about HIV
- Information about the test and the window period
- Stigma-sensitive discussion about risk and transmission
- Patient is prepared for test result
- Informed consent

Indications for testing

HIV testing is a normal part of preventive health care. GPs should consider discussing HIV testing with all patients, including those who don't present with risk factors for HIV. Patients may choose not to volunteer

risk factors due to embarrassment or stigma.

Testing is recommended for people with risk factors for HIV, which include: gay/bisexual men; anyone with recent partner change; history of unprotected sex with a person whose HIV status is unknown; recent diagnosis of an STI; people from (or with partners from) high-prevalence countries; and people who inject drugs. The absence of a risk factor should not preclude HIV testing.ⁱⁱ

Confidentiality and notification

Explain clearly how your service manages health records and privacy.

Provide brief state/territory specific information about notification of HIV positive results.ⁱⁱⁱ

Testing history

Ask about the patient's history of testing to help identify HIV health literacy and establish the timeframe for any risk discussion.

Health literacy and basic information about HIV

Use open-ended questions and support patient health literacy.

Reiterate or clarify basic information about HIV, such as *What is your understanding of HIV?*

Explanation of the HIV test and window period

Repeat HIV testing is recommended for people who may be in a test window period.

The window period for the 4th generation HIV test is within six weeks.

Rapid test (point of care and self-tests) and 3rd generation HIV test window periods can vary and are often up to three months.

Stigma-sensitive discussion about risk and transmission

Use respectful, non-judgemental language when discussing risk factors. Direct questioning about risk practices is not required for testing and may

cause discomfort for both the clinician and the patient.

Be aware of cultural sensitivities around discussing sexual practices. If there is discomfort it may help to mention sexual transmission briefly and provide further detail in written format.

Explain transmission in a way that allows the patient to generalise to their individual circumstance.

Consider discussing pre-exposure prophylaxis (PrEP) with people that have significant ongoing risk factors for HIV. All people at risk of HIV should be aware of or offered PrEP in accordance with the Australian PrEP guidelines.

Patient is prepared for test result

Explain how results will be given. If results will not be given in person, discuss where to get further information, and reiterate the need for repeat testing if tested in a window period.

Many people are concerned about the possibility of a positive result and they should be given the opportunity to explore these concerns.

If appropriate, refer to state/territory HIV peer support service.

Informed consent

Has the person had an opportunity to assess the personal implications of having the test today? Ensure the patient understands HIV and the testing process to the extent required to gain informed consent.

A lack of informed consent prior to testing is likely to increase the shock and distress of a positive result and may negatively impact engagement with care.

Notes

- i. The National HIV Testing Policy states that 'The absence of an identified epidemiological or behavioural risk factor should not preclude HIV testing in appropriate clinical circumstances. While a detailed sexual and/or drug use history may elevate the need for HIV testing, obtaining a detailed

history is not a prerequisite for testing.'

- ii. A full list of indicator conditions is available at http://testingportal.ashm.org.au/resources/Indicator_table_v1.1.pdf
- iii. HIV notifications are anonymised in Victoria, NSW, Queensland and the ACT. All other jurisdictions may require the full name of the newly diagnosed person.

Further reading

Johnson, J. and E Lenton, [HIV and hepatitis pre and post test discussion in Victoria- Consultation report](#). 2017: Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University.

Initiating HIV Testing - talking testing resource

https://www.latrobe.edu.au/_data/assets/pdf_file/0009/972234/Talking-Testing-HIV.pdf - tool

Australian Government, [National HIV Testing Policy](#) D.o.H.A., Editor. 2017, Commonwealth of Australia: ACT.

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5. Bell, S., et al., HIV pre-test practices: an online survey examining perceptions of informed consent

and pre-test information delivery in health care settings across the WHO European Region. *International Journal of STD & AIDS*, 2016. 28(6): p. 558-563.

6. Flowers, P., et al., Has testing been normalized? An analysis of changes in barriers to HIV testing among men who have sex with men between 2000 and 2010 in Scotland, UK. *HIV Medicine*, 2013. 14(2): p. 92-98.
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