

OPT-OUT (PROVIDER INITIATED) ROUTINE HIV TESTING

ACON Position Paper – October 2023

ACON supports the implementation of opt-out testing trials to establish whether significant advances in rates of diagnosis can be shown in NSW. This research should consider appropriate targeting, cost-effectiveness, and implementation approaches that will support informed consent, health literacy, service referrals and HIV stigma reduction.

In the event trials result in significant increases in diagnosis, ACON recommends implementation of opt-out testing with rigorous guidelines around informed consent, follow-up service linkage, and in conjunction with broad scale efforts to improve HIV health literacy.

BACKGROUND

What is opt-out testing?

'Opt-out' HIV testing, also referred to as provider-initiated testing, or routine HIV testing, occurs when a person who is having their bloods tested understands they will also automatically be tested for HIV unless they explicitly decline.

Under these circumstances, consent is considered to be obtained when the person has been advised, either through verbal, written, or electronic means, that HIV testing is performed routinely, but that it is voluntary, and the patient has the right to opt-out if they so choose.¹

Policy context

In a 2004 joint statement UNAIDS and the WHO distinguish between four types of HIV testing: voluntary, diagnostic, routine, and mandatory.²

Currently, in countries where opt-out testing has been implemented, it is primarily conducted in perinatal settings and hospital emergency departments in areas of high prevalence, however it is also conducted more widely in some countries in settings where a person is being screened for an STI or tested for tuberculosis, and in clinical and community health service settings where HIV is prevalent.

The basic conditions of confidentiality, consent, and counselling apply and the minimum amount of information that must be given to confirm informed consent is information on the benefits of testing, follow-up services available to anyone testing positive, the importance of informing anyone who may have been unknowingly exposed, and that the patient retains the right to refuse/opt-out of testing.

Health Equity Matters (HEM) advise that opt-out testing can increase testing rates for marginalised people and that it is shown to be

$$\left[\begin{array}{c} \text{TEST} \\ \text{OFTEN} \end{array} \right] + \left[\begin{array}{c} \text{TREAT} \\ \text{EARLY} \end{array} \right] + \left[\begin{array}{c} \text{STAY} \\ \text{SAFE} \end{array} \right] = \left[\begin{array}{c} \text{ENDING} \\ \text{HIV} \end{array} \right]$$

acceptable to both clients and clinicians. They prioritise implementation of opt-out HIV testing in settings of high HIV prevalence in their Agenda 2025.³

The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) published an update to their National HIV testing policy that includes support for opt-out HIV testing in GP and emergency department settings, as well as in STI, perinatal, and TB services with an emphasis on those that serve the most at-risk populations.¹

In their National Testing Policy, ASHM recommends opt-out testing as a feasible strategy for identifying people with previously undiagnosed HIV who may not otherwise access HIV testing services.⁴

International examples

Opt-out HIV testing in perinatal services was implemented in the UK in 2000, and researchers from the US and the UK have recommended the expansion of opt-out HIV testing to areas of high prevalence as far back as 2006.

The UK Government committed to supporting opt-out testing in emergency departments in 2021 and the practice has been effective in reaching populations with disproportionate rates of late diagnosis.⁵

In 2023 a number of organisations in the HIV sector in the UK called on the government to expand the practice, as the rollout has produced significant increases in new diagnoses among priority populations.⁶

Uptake by hospitals in the UK was significantly affected by whether a dedicated clinician or peer-support worker was stationed at the clinic or hospital to manage informed consent, notifications, and the additional workload of implementing the program.⁷

Opt-out testing vs mandatory disease testing (MDT)

Routine opt-out testing is differentiated from mandatory testing in the following ways:

- It is offered rather than enforced.

- There are minimum requirements for the provision of information in order to be classified as consensual.

- There is a requirement to provide the right to refuse.

In addition, opt-out testing is recommended to be conducted in clinical or community health service settings, rather than in legal or police-controlled settings.

Opt-out testing requires the provision of clear and accurate information about rights and processes.

ACON continues to oppose mandatory testing.

BENEFITS AND CHALLENGES ASSOCIATED WITH OPT-OUT HIV TESTING

Consent

Informed consent should only be confirmed if the person undergoing testing is proficient in the language the information is provided, particularly if notification of routine testing is only communicated via signage, pamphlet, or consent form.

If a culturally safe interpreter cannot be engaged, testing should not be performed. Opt-out testing should not be conducted if a person is intoxicated, unconscious or in an incapacitated state at the time their bloods are drawn.

Consideration should be given to the issue of consent in instances where a person may feel pressure to agree to testing based on their assumptions about how explicit decline may be perceived by the healthcare worker. It should also be considered whether a person with little HIV health literacy is in fact capable of providing meaningful consent.

Follow-up support

Particular attention should be given to the processes and referral pathways required to ensure appropriate linkage to services for anyone who tests positive. Procedural guidelines on how to communicate positive results, as well as immediate and appropriate support and discussion with the person about their diagnosis,

and, if relevant, their sexuality and gender identity are needed to ensure they are linked in to appropriate gender and sexuality affirming follow-up services.

In NSW, ACON offer peer-support services for LGBTQ+ people living with HIV (PLHIV), while POZHET provide services for heterosexual PLHIV, and Positive Life NSW offer support for all PLHIV. Referring doctors and clinicians must be aware of which services are appropriate for any newly diagnosed patient and trained to safely navigate these questions when making decisions about referral pathways.

Dedicated and trained staff to manage informed consent and follow-up support are necessary to ensure the additional workload of testing can be managed, particularly in hospital emergency departments, but also in busy clinical settings.

Stigma

For many, stigma remains one of the most significant barriers to engaging with prevention, testing and treatment interventions and reducing stigma and discrimination is one of the key pillars of the *NSW HIV Strategy 2021-2025*.⁸

If opt-out testing is to be initiated within the wider community this should occur alongside efforts to increase HIV health literacy for both healthcare workers and for the general community, to reduce stigma and discrimination and to raise awareness around modern treatments and outcomes.

This will be particularly important in communities where current understanding of HIV is low and misunderstanding about how an HIV diagnosis may adversely affect visa status is widespread.⁹

Rates of testing and cost

Opt-out testing has been shown to increase overall rates of testing, numbers of new diagnoses, and rates of re-engagement of people with prevention, testing and treatment services who may have dropped out of treatment, or lost contact with services over time.^{5,7}

The cost of implementing opt-out testing is significant; however, it is argued to be

significantly lower than the cost of treatment for those who may have otherwise gone undiagnosed for an extended period and later presenting with late-stage diagnosis.

Opt-out testing may be more easily and cost effectively deliverable to populations with high prevalence of late diagnosis when compared to large scale, targeted health campaigns aimed at encouraging people to come forward of their own volition.

The cost of testing at scale may be high if testing is not targeted towards high prevalence locations and may be perceived as a significant increase in operational costs for emergency departments, or busy general practice clinics in the immediate term. However, the benefits for communities experiencing high prevalence of people presenting with late-stage HIV complications should be considered over the long term.

Who does opt-out work best for?

Opt-out testing is most beneficial for people most at risk of late-stage diagnosis, those at risk of HIV who are not engaged in regular testing, as well as those who may have dropped out of regular testing or other forms of care.

Opt-out testing will be most beneficial if implemented in areas of high prevalence and for people with high-risk behaviours who are not currently engaged with prevention or testing interventions.

It may also benefit those who face high levels of stigma from their healthcare providers who may be too fearful of exposing themselves as sexuality or gender diverse to explicitly request an HIV test, or to request information on prevention, testing and treatment directly.

Low health literacy has been linked to increased compliance with the advice of health care providers.¹⁰ If rolled out with robust guidelines it is possible that this form of testing may contribute to an increase in accessibility of accurate health information for those with low understanding of HIV. Those with low HIV health literacy may otherwise be accessing outdated information circulating within the wider community that may perpetuate stigmatising or

prejudiced attitudes towards PLHIV. This is another reason opt-out testing should occur alongside efforts to increase HIV health literacy.

Who is less served by opt-out?

Opt-out testing does not benefit those who already know their status. It may be particularly detrimental for those living in communities where stigma is high, who may need a blood test for something unrelated to HIV, and strongly fear exposing themselves as LGBTQ+ to their healthcare provider. This may result in hesitancy to seek out any form of healthcare that requires blood testing.

Opt-out testing may be less beneficial for those who may feel pressured to consent to testing because they have low health literacy around HIV or who may be unable to read the health messaging provided.

Opt-out testing may not provide the same level of benefit in areas with low HIV prevalence. This is because testing a larger number of people in these locations requires significant investment of time, money, and labour yet may yield fewer, if any, undiagnosed cases due to the lower prevalence of the virus.

Opt-out testing may also be less beneficial for those who are concerned about their visa status and fearful of how a positive HIV test may affect their application for permanent residency in Australia.

This is a complicated issue because all people applying for permanent residency must have an HIV test, so avoiding testing will not result in a different outcome. However, misunderstanding and misinformation may still prevent many from participating in opt-out testing if they fear it will obstruct access to visas.

For this and many other reasons, ACON, in line with our partners, recommends removing all visa restrictions for people living with HIV and mandatory HIV testing associated with permanent residency application in Australia. Countries such as the US, UK, and New Zealand have all removed such restrictions.⁹

EMPOWERING COMMUNITIES TO PARTICIPATE IN OPT-OUT TESTING

Evidence from the US and the UK indicate that opt-out HIV testing has been successful under certain conditions, particularly when targeted towards areas of high prevalence of HIV.

To gain support for, and participation in, opt-out testing, providers must encourage the community to be aware of their right to ask questions and to discuss their concerns.

To achieve this, services must:

- Give clear information about the right to opt-out alongside an explanation of the benefits of regular testing in language that is accessible to the person.
- Provide comprehensive support in the case of a positive result.
- Link patients to follow-up peer-support services that are appropriate and affirming of their sexuality and gender.
- Mandate LGBTQ+ inclusivity training in clinical settings where opt-out testing is delivered, to ensure inclusive and welcoming healthcare environments, particularly in areas known to exhibit high rates of stigma and prejudice towards LGBTQ+ people, including for interpreters.

ACON recommends that alongside opt-out testing, broad scale efforts to improve HIV health literacy are also undertaken.

Modern HIV prevention, testing and treatment interventions mean it is not only possible, but also safe and easy to get treatment and to maintain an undetectable viral load, and because undetectable equals untransmissible (U=U), there is zero risk of transmitting HIV to a partner.

Increasing HIV health literacy would help promote the benefits of an opt-out approach and encourage uptake as well as the normalisation of regular, routine HIV testing.

Raising health literacy around HIV will also help to address persistent stigma within the community caused by outdated understandings of HIV.

REFERENCES

1. The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM). (2022). *HIV Testing Policy Update: Opt-out Testing*. <https://ashm.org.au/news/hiv-testing-policy-update-opt-out-testing/>
2. UNAIDS, & WHO. (2004). *Policy Statement on HIV Testing*. https://data.unaids.org/una-docs/hivtestingpolicy_en.pdf
3. Health Equity Matters (HEM). (2021). *Agenda 2025: Ending HIV Transmission in Australia*. <https://healthequitymatters.org.au/wp-content/uploads/2021/06/Agenda-25-Technical-Paper.pdf>
4. The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM). (2020). *National HIV Testing Policy*. https://testingportal.ashm.org.au/files/ASHM_National%20HIVTestingPolicy_2020_HIV_.pdf
5. The Lancet HIV. (2022). Levelling up HIV testing for the endgame. *The Lancet HIV*, 9(5), e299. [https://doi.org/10.1016/S2352-3018\(22\)00106-0](https://doi.org/10.1016/S2352-3018(22)00106-0)
6. Terrance Higgins Trust UK. (2023). *Thousands call on Government to expand opt-out testing for HIV and Hepatitis*. <https://www.tht.org.uk/news/thousands-call-government-expand-opt-out-testing-hiv-and-hepatitis>
7. The Lancet HIV. (2023). Opt-out HIV testing in the UK. *The Lancet HIV*, 10(6), e351. [https://doi.org/10.1016/S2352-3018\(23\)00117-0](https://doi.org/10.1016/S2352-3018(23)00117-0)
8. NSW Ministry of Health. (2020). *NSW HIV Strategy 2021-2025*. <https://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2021-2025.pdf>
9. Timms, P., & Young, E. (2023, July 24). Time for Australia to drop visa restrictions for migrants living with HIV, advocates say. *ABC News*. <https://www.abc.net.au/news/2023-07-24/remove-hiv-visa-restrictions-advocates-say/102622198>
10. Barragán, M., Hicks, G., Williams, M. V., Franco-Paredes, C., Duffus, W., & Rio, C. (2005). Low health literacy is associated with HIV test acceptance. *Journal of General Internal Medicine*, 20(5), 422–425. <https://doi.org/10.1111/j.1525-1497.2005.40128.x>

$$\left[\begin{array}{c} \text{TEST} \\ \text{OFTEN} \end{array} \right] + \left[\begin{array}{c} \text{TREAT} \\ \text{EARLY} \end{array} \right] + \left[\begin{array}{c} \text{STAY} \\ \text{SAFE} \end{array} \right] = \left[\begin{array}{c} \text{ENDING} \\ \text{HIV} \end{array} \right]$$