

# ‘We didn’t have to dance around it’: opt-out HIV testing among homeless and marginalised patients

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**Abstract.** This study explored opt-out HIV testing in an Australian general practice. The aims were to: (1) determine the effect of the opt-out approach on the number of HIV tests performed; and (2) explore the acceptability of opt-out HIV testing from the healthcare providers’ perspective. A prospective mixed-methods study of opt-out HIV testing over a 2-year period (March 2014–March 2016) was conducted. Implementation was based on a theoretical framework that was developed specifically for this study. The setting was Homeless Healthcare, a health service in Perth, Western Australia. The number of HIV tests conducted during the control year (usual practice) was compared with the intervention year (opt-out testing). After the intervention, the healthcare providers ( $n=8$ ) were interviewed about their experiences with opt-out HIV testing. Directed content analysis was used to explore the qualitative data. HIV testing rates were low during both the control year and the intervention year (315 HIV tests (12% of the patient cohort) and 344 HIV tests (10%) respectively). Opt-out HIV testing was feasible and acceptable to the participating healthcare providers. Other health services could consider opt-out HIV testing for their patients to identify people with undiagnosed infections and sustain Australia’s low HIV prevalence.

**Additional keyword:** Australia.

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## Introduction

In opt-out HIV testing, healthcare providers inform patients that they are going to be tested for HIV unless they decline or defer (Branson *et al.* 2006). Over the past decade, opt-out HIV testing has become routine in some countries (Viall *et al.* 2011) and is recommended for pregnant women in Australia (Royal Australian and New Zealand College of Obstetricians and Gynaecologists 2015). Research from the United States, the United Kingdom, Spain and other countries has shown that opt-out testing is feasible and acceptable to both patients and healthcare providers (Bath *et al.* 2015; Navaza *et al.* 2016). Although Australia has been recognised for its leadership in HIV prevention, to our knowledge, opt-out HIV testing has never been explored in Australian general practice. Our previous study of Australian healthcare providers’ views on opt-out HIV testing found that half of the participating GPs questioned the acceptability and feasibility of the approach (Leidel *et al.* 2015).

On this basis, we conducted a trial of opt-out HIV testing using a theoretical framework specifically developed to inform this study (Leidel *et al.* 2017). The framework integrates concepts from Behavioural Economics (Rice 2013), the foundation for the default-based (opt-out) study intervention; the Health Belief

Model, to explore possible relationships between the participants’ beliefs about HIV and their testing practices (Rosenstock 1974); and Normalisation Process Theory, a guide for implementation of opt-out HIV testing at the operational level (May 2013).

We conducted this study at Homeless Healthcare, a unique general practice in inner-city Perth, Western Australia. Homeless Healthcare runs street-based mobile clinics led by GP–nurse teams, providing health care for ~3000 homeless and marginalised patients each year. Its outreach service is led by a ‘street health’ nurse who identifies vulnerable people with urgent health needs and connects them to the mobile clinics, which are spread across seven different locations. Homeless Healthcare also runs a conventional GP surgery for people whose housing situation becomes more stable and an ‘in-reach’ service for homeless patients who are hospitalised. Risky behaviours that could result in HIV infection (such as injecting drug use) are common within the Homeless Healthcare patient cohort, so it was considered to be a valid site to explore opt-out testing. Our aims were to: (1) determine the effect of the opt-out approach on the number of HIV tests performed; and (2) explore the acceptability and feasibility of opt-out HIV testing from the healthcare providers’ perspective.

**What is known about the topic?**

- Opt-out HIV testing outside of Australia is acceptable to healthcare providers and has been shown to identify undiagnosed HIV infections.

**What does this paper add?**

- In the first study of opt-out HIV testing in Australia, healthcare providers in an Australian general practice for marginalised patients found the approach to be feasible and acceptable.

**Methods**

A prospective mixed-methods study of opt-out HIV testing was conducted at Homeless Healthcare over a 2-year period. Participants included GPs, nurse practitioners (NPs) and nurses (nurses were included because they take part in every consult at Homeless Healthcare, and their involvement has been shown to facilitate the implementation of opt-out HIV testing) (Leblanc *et al.* 2015). In the first phase (March 2014–March 2015), the healthcare providers conducted HIV testing according to their usual practice. They were not informed of the number of HIV tests that they performed during that year. In March 2015, we educated the same cohort of healthcare providers about opt-out HIV testing. During the intervention year (April 2015–April 2016), these providers performed opt-out HIV testing on patients having other blood tests (e.g. ‘we are going to test you for HIV unless you do not want to be tested’). If the patient did not opt-out, the healthcare provider obtained a blood sample by venepuncture, which was sent to a laboratory and tested with a HIV-1 and -2 antibody and antigen assay. The participants did not record the number of HIV tests that they performed and did not receive feedback about their testing practice during the intervention. At the end of the intervention, we obtained de-identified HIV testing data

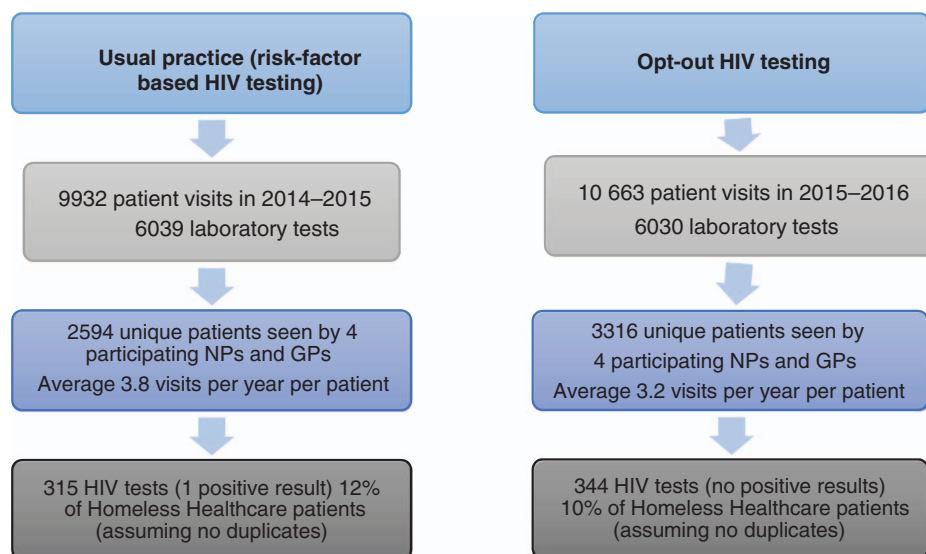
from the laboratory that performs all blood testing for Homeless Healthcare. We then compared the number of HIV tests done before the intervention (usual practice) and during the intervention (opt-out testing).

To explore the healthcare providers’ experiences with opt-out HIV testing, we interviewed the participants after the intervention period. A semi-structured interview guide and coding scheme was developed according to our opt-out HIV testing theoretical framework (Appendix 1) (Leidel *et al.* 2017). The primary researcher de-identified, transcribed and coded the interviews using directed content analysis (Hsieh and Shannon 2005). An experienced qualitative researcher (SG) then reviewed the coding. We resolved coding discrepancies through discussion. Data were managed with NVivo (ver. 11, QSR International, Melbourne, Vic., Australia). This study was approved by the Human Ethics Research Committee of the Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia.

**Results***Number of HIV tests performed: usual practice versus opt-out*

Three GPs, four practice nurses and one nurse practitioner provided written consent to participate in the study, representing the majority of clinic staff. From 1 April 2014 to 31 March 2015, the participating GPs and NP conducted HIV testing according to usual practice. During this period, they conducted 9932 patient visits, of which 2594 were unique patients. They performed 6039 laboratory tests, of which 315 were HIV tests (12% of the patients at Homeless Healthcare had HIV tests). There was one positive result (Fig. 1).

Between 1 April 2015 and 31 March 2016, the same cohort of providers conducted HIV testing on an opt-out basis for patients who were already having blood tests. During this period, there were 10 663 patient visits, of which 3316 were unique patients. They performed 6030 laboratory tests, of which 344 were HIV



**Fig. 1.** Number of patients, visits and HIV tests at Homeless Healthcare before and during opt-out testing.

tests (10% of the patients at Homeless Healthcare were tested). There were no positive results.

### Qualitative findings

After the intervention year, in May and June 2016, the primary researcher (S. Leidel) interviewed the eight participants by a video chat application. Interviews ranged from 20 to 44 min. By the eighth interview, no new concepts were surfacing.

We present the healthcare providers' experiences according to selected concepts (Fig. 2) from our opt-out HIV testing theoretical framework; these concepts were: HIV testing by default, provider self-efficacy, collective action and coherence, perceived barriers and perceived benefits (Leidel *et al.* 2017).

#### HIV testing by default

Participants said that the change to opt-out HIV testing (which is done without pre-test counselling) was not difficult. They found that patients did not expect an explanation other than being informed they would be tested for HIV test unless they declined.

I started saying we're doing opt-out testing for HIV, and I tried to explain it, and I just got weird looks [GP-3].

Offering HIV testing as a default meant that the healthcare providers did not enquire about the patients' risk factors, treating the HIV test like other routine blood tests. Deferring the risk factor assessment conveyed an open-minded attitude to patients and saved time and effort by taking 'that decision-making off our shoulders' [RN-1].

It's just part of providing a non-judgmental service [NP-2].

It actually gave us more time, because we didn't have to dance around it [RN-1].

It made it easier because it wasn't a matter of querying which clients were going to be offered it or not, it was just a routine thing [RN-7].

#### Provider self-efficacy with opt-out HIV testing

Some participants stated that they were initially uncomfortable with opt-out HIV testing, but quickly became confident with it.

During the study period, I had my first ever positive HIV test. So that increased my confidence because I actually went through the process of referring [GP-5].

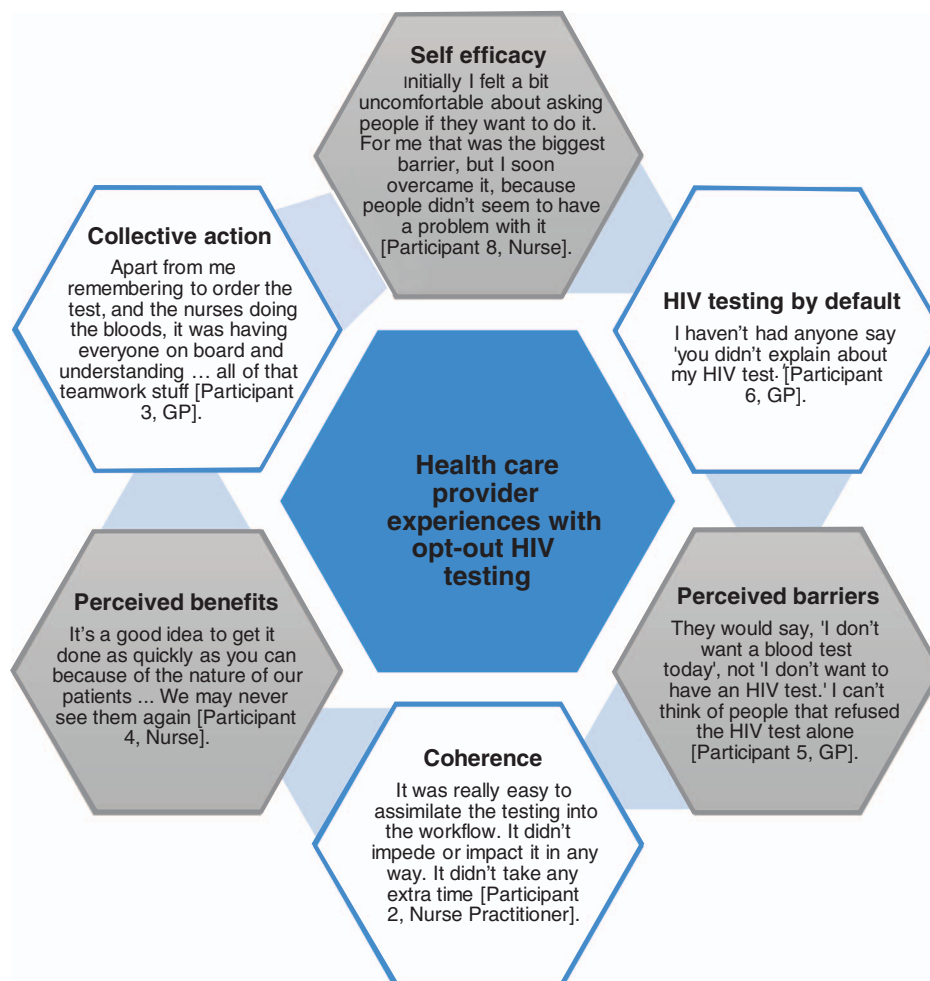


Fig. 2. Healthcare providers' views on opt-out HIV testing according to our theoretical framework.

Participants sometimes asked the patients if they would like to be tested for HIV, rather than informing them that they would be tested unless they declined. This subtle difference in syntax indicated a lack of self-efficacy with making opt-out statements.

We are doing these bloods, so do you want these [HIV] bloods as well? [NP-2].

Two GPs said that they had previously been doing a version of opt-out to facilitate HIV testing without recognising it as a distinct approach.

I've probably been unwittingly doing opt-out testing for a number of years, and in our client population, I've found that's the easiest way to go [GP-6].

#### *Coherence and collective action in the implementation of opt-out HIV testing*

Teamwork among healthcare providers facilitated the opt-out HIV testing program, particularly between the GPs–nurse teams running each mobile clinic.

In our practice we have the luxury of working really closely with nurses. I didn't need to say 'we're doing a HIV test', because the nurses see that it needs to be done [GP-5].

It didn't matter who you were working with, things were done in unison, there was teamwork, and it was you do this, I do that [RN-4].

#### *Perceived barriers to opt-out HIV testing*

Participants rarely encountered barriers to opt-out HIV testing. The most common barriers were provider discomfort with talking about HIV and convincing patients to have blood tests. Most participants said that no one opted out of HIV testing.

In the beginning the only barrier was feeling a bit uncomfortable doing it. I don't think I ever had someone say no, except for one who already had HIV [NP-2].

The barrier was convincing people to have blood tests. If they were willing to have a blood test, they were willing to have an HIV test [GP-6].

## **Discussion**

HIV testing rates were low among Homeless Healthcare patients during the control year (usual practice) and the intervention year (12 and 10% respectively). Given that up to 21% of HIV infections in Australia are undiagnosed (The Kirby Institute 2014), our data show that HIV testing rates could be improved, even in services like Homeless Healthcare that specialise in the treatment of marginalised groups. Other studies have found low HIV testing rates in high-risk groups, such as Indigenous Australians (Ward *et al.* 2016). Since 2011, notifications of HIV among Indigenous Australian males have increased steadily compared to non-Indigenous, Australian-born males, supporting the need for novel testing approaches (The Kirby Institute 2016).

The number of HIV tests performed with usual practice and the opt-out approach were remarkably similar. One reason may

be that some of the participants had started to abbreviate pre-test counselling and risk factor assessment before the intervention began, essentially performing opt-out testing without recognising it as a shift in practice. Some participants did not always use the exact opt-out wording that they had learned for the pilot test, or phrased the opt-out statement as a question when gaining consent (Australasian Society for HIV Medicine 2014). They may have been uncomfortable with opt-out HIV testing even if they supported it conceptually, perhaps because they were taught to do pre-test counselling during their training and it had become embedded in their practice. Discomfort with introducing HIV tests to patients has been documented among nurses doing opt-out HIV testing in several countries (Evans *et al.* 2015) and among healthcare providers in the US (Christopoulos *et al.* 2011). Providers who were less comfortable with the opt-out approach may have done fewer HIV tests because they modified the way the test was offered, contributing to the reasonably constant number of opt-out HIV tests compared to usual practice.

Access to health care is associated with increased HIV testing (Thomas *et al.* 2010). In our study, the number of HIV tests did not increase during the opt-out period, which may be related to the patients' access to health care; some patients may not have had blood tests during the study period because they had already been tested for HIV. By offering non-judgemental services in areas of greatest need, Homeless Healthcare is able to engage marginalised people who would not normally have access to health care. With each patient having an average of three GP visits per year, homeless individuals had an opportunity for health screening (including HIV testing) and harm-reduction education, which may have been a factor in the low incidence of HIV in this study.

The number of HIV tests performed with the opt-out method did not decrease substantially from the previous year, suggesting that few patients opted out of HIV testing. Although this study was not designed to capture the number of patients who opted out, most participants stated that patients rarely declined (except for people who did not want to have blood tests done at all or reported that they were HIV positive). Studies from diverse settings around the world have shown high patient acceptance of opt-out HIV testing (Haukoos *et al.* 2008; Wilson d'Almeida *et al.* 2013; Montoy *et al.* 2016). This is the first Australian study to demonstrate that marginalised patients are accepting of the opt-out method.

Our previous study of Australian healthcare provider views on opt-out HIV testing identified a subset of healthcare providers who thought that it was not feasible or acceptable (Leidel *et al.* 2015). This study demonstrated that the opt-out approach is feasible and acceptable to healthcare providers and patients in a general practice that focuses on at-risk patients. Consistent with international research findings, opt-out HIV testing did not disrupt workflow or impede other clinical activities (Solomon *et al.* 2014). The healthcare providers in this study reported that the opt-out HIV testing program was easy to implement, saved time and removed the task of performing a risk assessment and pre-test counselling on every patient.

Our findings also add to the body of evidence showing Australia's successful response to its HIV epidemic. We found a very low incidence of HIV in a general practice with over 3000



vulnerable patients (many of whom likely engage in high-risk behaviours), highlighting the undeniable achievements in HIV prevention in Australia. New HIV infections peaked in Australia in 1987 and decreased steadily until 1999 (The Kirby Institute 2014), largely due to the success of needle syringe programs, preventing an explosion of infections among injecting drug users (Madden and Wodak 2014). Decriminalisation of the sex industry and empowerment of sex workers has also contributed to Australia's low HIV prevalence (Bates and Berg 2014). HIV prevention initiatives, particularly school-based youth education campaigns, were instrumental in decreasing risk behaviours (Jones and Mitchell 2014). Despite these achievements, the small but steady rise in HIV infections over the past 17 years (The Kirby Institute 2014) indicates that new approaches (such as opt-out testing) are needed to sustain Australia's low HIV prevalence. Although this study has provided a preliminary view on opt-out HIV testing in the Australian context, the value of the approach should be studied across different groups. Patient acceptability of opt-out HIV testing should be investigated.

### Limitations

We did not obtain HIV testing data on individual patients, so it is possible that some patients were tested more than once (which is appropriate if they are at a high risk of infection), although duplicate tests would be unlikely to vary substantially from year to year. We were also unable to identify patient-initiated HIV tests from the laboratory data. Because the healthcare providers performed opt-out testing only on patients who were already having blood tests, we may not have captured the entire cohort of patients who could be HIV positive. Patients at highest risk of HIV infection may have been less likely to agree to any blood test. Rapid point-of-care HIV tests, which were approved in Australia in 2012 and do not require venepuncture, may help overcome this barrier (Chan et al. 2015). Whereas opt-out HIV testing was easily implemented in this particular general practice, we cannot make inferences about its acceptability or feasibility in other health services.

### Conclusion

We found that opt-out HIV testing was feasible and acceptable to healthcare providers in an Australian general practice that specialises in care for homeless and marginalised people. The number of HIV tests did not change substantially with the opt-out approach, suggesting that few patients opted out. Based on our findings, Australian health services could consider testing the feasibility of opt-out HIV testing for their patients (or a subgroup of patients) as a viable way to identify people with undiagnosed infections. Identifying these individuals and connecting them to HIV care would improve health outcomes and decrease onward transmission of the virus, which is necessary to sustain Australia's low HIV prevalence.

### Conflicts of interest

The authors declare that they have no conflicts of interest.

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#### Appendix 1. Interview guide for healthcare providers (HCPs) (conducted after the opt-out HIV testing study)

1. Describe your experience with opt-out HIV testing.
  - a. Prompts: time factors, resource constraints, issues related to pre-test counselling.
2. What facilitated the process of opt-out HIV testing?
  - a. Prompts: computer reminders, education sessions, staff engagement.
3. What barriers did you encounter?
  - a. Prompts: disrupted workflow, patients' lack of willingness, time constraints.
4. Did you have ethical concerns during the opt-out testing process?
  - a. Prompts: informed consent, confidentiality, privacy.
5. How do you think the default option affected the number of HIV tests that were performed?
6. How did you 'frame' the opt-out HIV test for your patients?
7. Did your beliefs about your patients' susceptibility to HIV change during the pilot test? If so, how?
8. What cues or reminders were helpful during the pilot test? [cues to action]
9. How confident are you that you can perform opt-out HIV testing, discuss results with patients and make referrals if needed? Did this confidence increase during the study period? [self-efficacy]
10. Describe how opt-out HIV testing became part of day-to-day practice. [coherence]
11. Describe how the HCPs worked together to perform opt-out HIV testing. [collective action]