

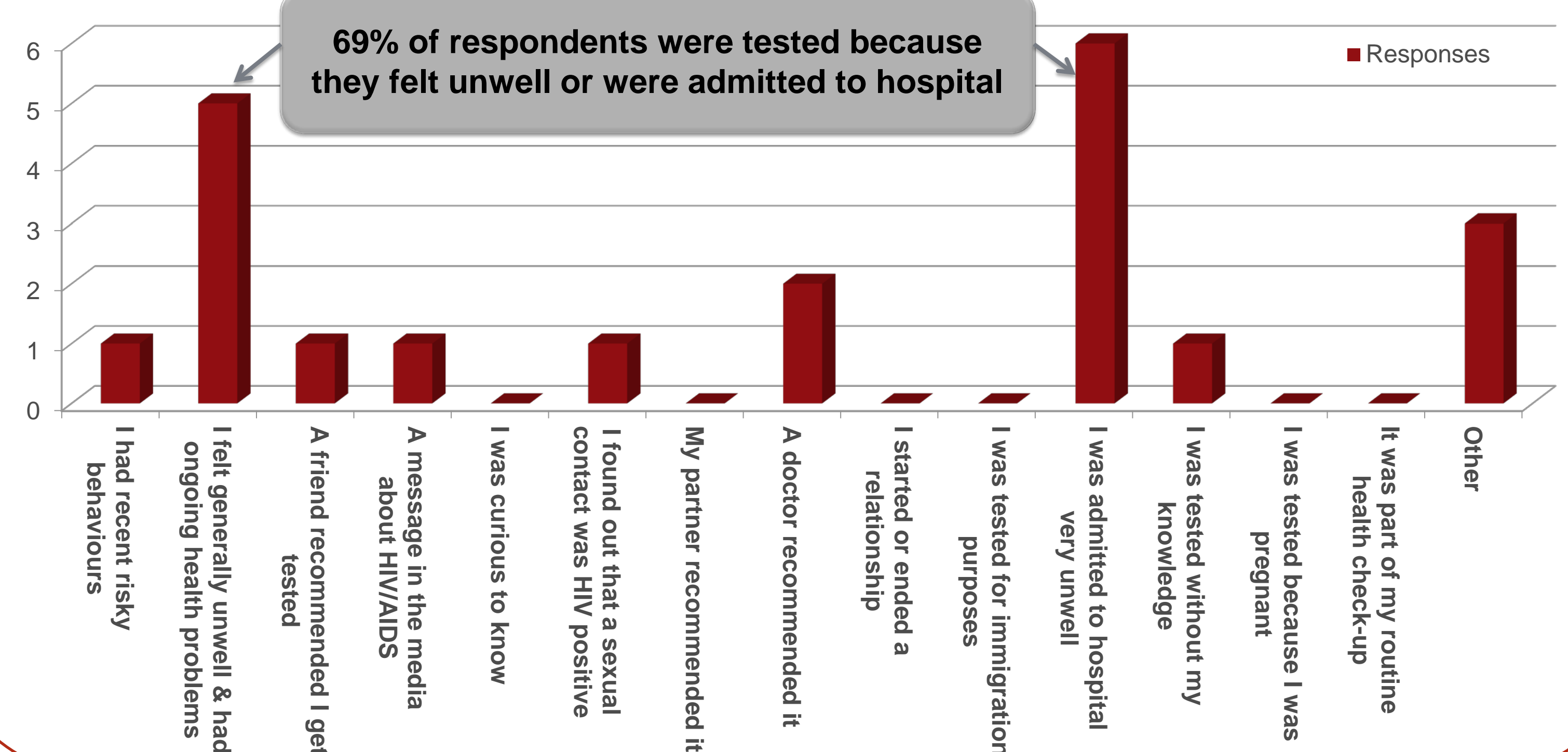
Latecomers: A regional pilot study of delayed HIV presentation

P Dobson^{1,2} R Riley¹ B Green³ M Boyle^{1,2}

1. John Hunter Hospital Newcastle NSW 2. Faculty of Health & Medicine University of Newcastle 3. HARP Health Promotion Tamworth



Reason that led to first positive test



Introduction

Delayed HIV presentation is a major risk factor for HIV related premature death or irreversible HIV neurological disease. Despite this risk, 20 years after the introduction of highly active antiretroviral therapy, and more than 30 years of targeted HIV testing education, delayed HIV diagnosis remains commonplace with late diagnoses 12% and advanced diagnoses 27% of all new diagnoses in our region 2010-2015.

Method

A 34 question survey was developed to determine:

- who in our cohort had delayed presentation,
- missed opportunities for earlier diagnosis,
- attitudes and knowledge around testing, and
- if there were interventions that would have made these clients present earlier.

Patients diagnosed from 2010-2015 presenting late (<350 CD4 cells or advanced HIV disease (≤ 200 CD4 cells) were identified from the client records of the John Hunter Hospital, Pacific Clinic Sexual Health Newcastle, or Tamworth Sexual Health Service. Consent was obtained.

Surveys were administered either in a face-to-face interview, telephone interview, online, or paper based survey.

Results

Who presented late?

Forty five participants met the CD4 count criteria for delayed presentation, eight were excluded (seroconversions, deceased, diagnosis date unknown). Of the remaining 37, 14 (38%) declined participation and 4 (9%) could not be contacted. Six participants agreed to participate but never returned their surveys.

13 respondents completed the survey

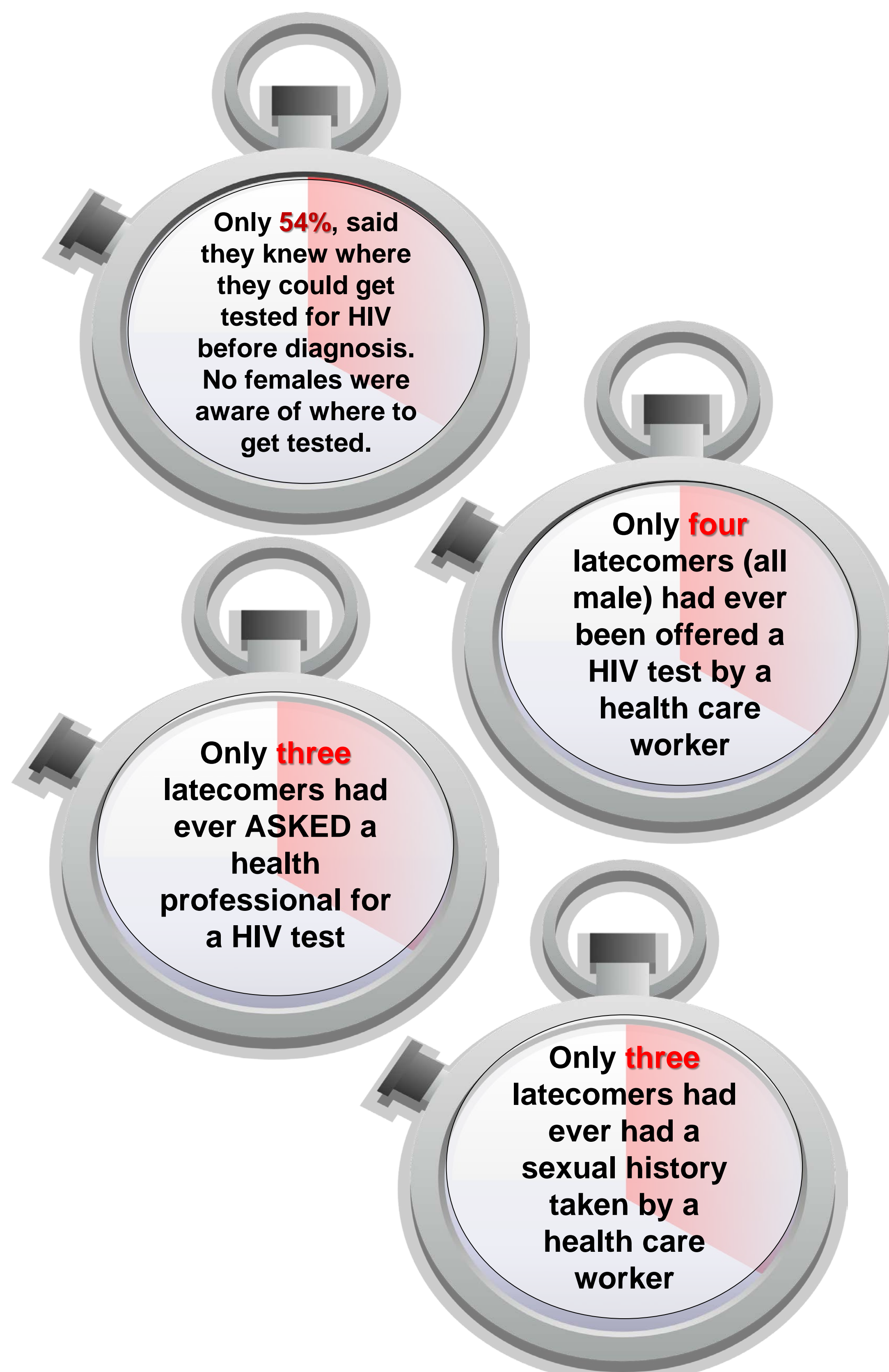
- 9 male (69%), 4 female (31%); 1 ATSI
- 3 born outside Australia; and speak a language other than English at home
- Self-identified by who they had sex with
 - Heterosexual 6; (female 4, male 2)
 - 4 MSM
 - 3 bisexual males
- Late presenters comprised (33%) and Advanced presenters (67%) of study participants
- Three diagnosed elsewhere (Morocco, Zimbabwe, Malaysia)

Risk Perception

When asked if they considered themselves to be at risk of getting HIV prior to their diagnosis, the majority of latecomers (61.5%), including all of the women, said not at all. Only one respondent, an MSM, felt that they were at high risk.

Only one latecomer knew someone else with HIV before their diagnosis

Missed Opportunities



Attitudes and Knowledge

We asked respondents to agree or disagree with the following statements:

I think it is better to find out that you have HIV as soon as possible after getting infected. 100% agree

I think it is better to be diagnosed EARLIER so that you can start treatment earlier to prevent the virus doing too much damage to the body. 100% agree

I think that if you are diagnosed LATER you don't have to spend all those extra years worrying about what HIV is going to do to you. 10 of 13 disagree. 3 of 4 females agree

What would have encouraged latecomers to be tested earlier?

What would have encouraged latecomers to be tested earlier?	% of responders
Greater access to testing facilities	20%
More general information about testing	50%
More education about current HIV treatment and care	30%
Nothing would have encouraged me to be tested earlier	30%
The availability of a rapid test	20%
A safe place to talk with a health professional about whether testing is recommended	40%
A confidential place to be tested	40%
Other (please specify)	
- Contact with others with HIV	10%
- More reliable online information	10%
- My doctor only had to get me checked earlier	10%
- Medical advice about what the symptoms I was experiencing could mean	10%
Nil response	30%

Conclusion

Around 70% of respondents believed that they had no risk or a small risk of acquiring HIV, and the majority identified a lack of information or education on HIV and testing a factor impacting on their delayed diagnosis. Given the serious consequences of delayed presentation, we recommend that:

- testing and treatment outcomes information be made accessible to wider populations than is currently available
- testing should be offered more opportunistically
- safety and confidentiality around testing be maintained.

Corresponding author: richard.riley@hnehealth.nsw.gov.au

Acknowledgements

The authors would like to thank Eril Singer for interviewing patients; Dr Nathan Ryder and Kylie Voght from Pacific Clinic Newcastle and Grant Sweeney from Tamworth Sexual Health for assistance recruiting patients.

Disclosure of Interest Statement

The research was supported by Dr Michael Boyle's AIDS education & research fund. No industry support was obtained for the conduct of this research project.



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