Why Do Some Patients Refuse HIV Testing?

Professor Graham Hart
Director
Centre for Sexual Health & HIV Research
Research Department of Infection & Population Health
University College London

How Do We Increase Acceptability & Uptake of HIV Testing?

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CONTEXT

• UK has poor uptake of HIV testing in high risk populations compared to other developed countries
  
  ? MSM in UK (50 – 75% ever tested)*
  
  ? MSM in US (92% ever tested)**
  
  ? MSM in Australia (>90% ever tested)***

*Williamson L et al. JAIDS 2006;42:238-241
***Prestage G et al. Sexual Health 2008;5:119-123

OVERVIEW

• Reasons for not having a test

• Challenges to increased testing

• Increasing uptake

• Conclusions
REASONS FOR NOT HAVING A TEST

MRC Social & Public Health Sciences Unit: 2002 Gay Men’s Sexual Health Survey (N=1734)

Hart & Williamson
<table>
<thead>
<tr>
<th>Ever had an HIV test</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>888</td>
<td>53.9</td>
</tr>
<tr>
<td>No</td>
<td>758</td>
<td>46.1</td>
</tr>
<tr>
<td>Total</td>
<td>1646</td>
<td>100.0</td>
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</tbody>
</table>

Hart & Williamson
MRC Social & Public Health Sciences Unit: 2002 Gay Men’s Sexual Health Survey (N=1734)

<table>
<thead>
<tr>
<th>Of those tested</th>
<th>Recency of HIV test</th>
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<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>Tested in last 12 months*</td>
<td>404</td>
</tr>
<tr>
<td>Not tested in last 12 months</td>
<td>422</td>
</tr>
<tr>
<td>Total</td>
<td>826</td>
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</tbody>
</table>

*This includes all men tested in 2001 or 2002

Hart & Williamson
### Reasons for not having an HIV test

<table>
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<tr>
<th>Reason</th>
<th>All men who have not tested in last 12 months (N=1025)</th>
<th>Men who've never had an HIV test (N=718)</th>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
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</tr>
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<td>I'm certain I know my HIV status</td>
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<td>40.0</td>
<td>262</td>
</tr>
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<td>I haven't put myself at risk of HIV infection</td>
<td>456</td>
<td>44.5</td>
<td>327</td>
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<tr>
<td>I don't want to know if I have HIV infection</td>
<td>109</td>
<td>10.6</td>
<td>86</td>
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<td>77</td>
<td>7.5</td>
<td>71</td>
</tr>
<tr>
<td>I don't want others to know (e.g. insurance)</td>
<td>54</td>
<td>5.3</td>
<td>39</td>
</tr>
<tr>
<td>I'm too frightened of the results</td>
<td>154</td>
<td>15.0</td>
<td>125</td>
</tr>
<tr>
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*Men tested prior to 2001.

Hart & Williamson
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Hart & Williamson
Undiagnosed HIV infection in MSM in community samples in the UK, 2003-5

Of the HIV positive men in Glasgow & Edinburgh (n=60)

- 35 (58%) reported their last HIV test was positive
- 18 (30%) reported their last HIV test was negative
- 3 (5%) reported having a test, but not the result
- 4 (7%) had never been tested

Undiagnosed HIV Infection

Of the HIV positive men in Glasgow & Edinburgh (n=60)

- Undiagnosed HIV infection in 25 (42%)
- Of these, 14 (56%) had previously had a negative test and perceived their current status to be negative


Undiagnosed Infection by Clinic Use / STI in previous year

Undiagnosed HIV infection in MSM in community samples in the UK, 2003-5

Compared with HIV-negative men (OR 1.0), the adjusted OR of unprotected anal intercourse with 2 or more partners was:

- higher among undiagnosed men (OR 2.21, 95% CI 1.17–4.20)
- but highest among diagnosed men (OR 6.80, 95% CI 4.39–10.52)

CHALLENGES TO INCREASED HIV TESTING

- For men who have sex with men
- For people of African origin
Stigma

I was talking to somebody in the pub once, chatting to them, and somebody I sort of not know very well came up to me and said ‘Oh, you’ve got to watch him, he’s got HIV’……..I’m like ‘Well fuck off, so have I’

(MSM; Body Positive, Focus Group)


Stigma

I think that back to that scenario again where you know people find out [that sex with a known positive partner has occurred] then you’d be tarred with the same brush. And oh……..you just can’t have that, otherwise your name will be branded……and you will be segregated from the rest.

(MSM; HIV untested)

Consequences

There are people who are living here illegally……..that person can never get tested. They could even fall sick and still not get tested until they are actually helpless themselves and they have to be taken to hospital. Because they are so much afraid of the law. Of the consequences of being sent back …”

(HIV positive African Man, late 30’s)

Burns, F. Study of Newly diagnosed HIV In Africans (SONHIA)

Consequences

R: I’m not worried about the virus – my worry is whether I will be allowed to remain here in this country.
I: OK – why is that the case?
R: Because I know if I go back I will not have any medication…they’ll (just) send me to bed. That’s my only worry. But otherwise, after seeing how people live with the virus here, if I have same care, now I can still live.

(African man, mid-30’s)

Consequences

Most of the reason I had to abandon my previous life, my job and everything I believed in (was) because I had to make a decision between staying and accessing medications or going back where there is no medication and risking (death). I had to make a choice so I had to forfeit everything I believed in for the sake of staying alive.

(HIV positive African Man, late 30's)

B. An HIV test should be considered in the following settings where diagnosed HIV prevalence in the local population (PCT/LA) exceeds 2 in 1000 population:

1. All men and women registering in general practice
2. All general medical admissions

The introduction of universal HIV testing in these settings should be thoroughly evaluated for acceptability and feasibility and the resultant data made available to better inform the ongoing implementation of these guidelines.
Rapid HIV Testing in Primary care: Acceptability & Feasibility

The RHIVA Study

Audrey Prost PhD
MRC Social & Public Health Sciences Unit
& Centre for Sexual Health & HIV Research (UCL)

Study objectives

• To measure the uptake of rapid HIV testing among new patients aged 18 -55 registering with a London GP surgery during the study period (Dec 2007 – March 2008)

• Explore acceptability – qualitative interviews

• Assess feasibility – pilot study
Rapid HIV test

- OraQuick Advance HIV-1/2
- Carried out on oral mucosal fluid
- Results in 20 minutes
- Quality assurance scheme - Royal Free Hospital

Participation in the study

<table>
<thead>
<tr>
<th>Patients attending health check</th>
<th>Patients eligible</th>
<th>Patients tested</th>
<th>Patients interviewed</th>
<th>Reactive rapid HIV test</th>
</tr>
</thead>
<tbody>
<tr>
<td>111</td>
<td>85</td>
<td>38</td>
<td>20</td>
<td>1</td>
</tr>
</tbody>
</table>
Rapid HIV testing

- 36% (17/47) of patients who refused a test said ‘I am not at risk for HIV – study not relevant to me’
- 19% (9/47) said they had had a test recently
- 79% (30/38) of those who tested said they did so ‘because it is part of a health check-up’
- Among those who tested, rapid HIV tests on oral fluid were seen as highly acceptable

Qualitative results

- 20 semi-structured interviews
- 3 with patients who did not test
- 14 had had an HIV test before
- All interviewees felt that having a rapid HIV test in primary care was acceptable
- Differing views about best time to offer the test and who should give results
Advantages

Reductiong the wait for results

I think that what I remember about HIV tests was the wait. […] I don’t think that much can take away the stress of possibly testing positive for HIV, but I think that if you can close the gap between giving the initial sample and getting the result, it certainly would alleviate a lot of anxiety.

(Female participant, Canada, 35)

Advantages

Primary care more accessible than sexual health clinics

You know, sometimes to go to some AIDS clinic, once you go there, people just know what you’re [there] for. They know you most probably have some sexual disease going (on) down there. […] With a GP nobody knows, so you could be sick for anything. […] So I think it’s good if the GP (offers) it.

Nobody ever, ever offered me an HIV test. […] They will only find out in the hospital when I’m sick […] Before they find out, probably five, ten people, they’ve got it through me, but with a GP, you can easily find out […]

(Male participant, Nigeria, 28)
Advantages

*Primary care more accessible than sexual health clinics*

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(Male participant, Nigeria, 28)

Concerns

*Patients may be unprepared to test*

It is so quick, you know, 20 minutes […] especially if people hadn’t maybe even, you know, gone in for that test, and then kind of thought, “oh well I might as well try it”, and then, and I’m sure it’s a very sort of, small minority that actually would have a positive test, but you know, if they did, then it could be a real shock.

(Female participant, UK, 27)
Concerns

*Potential lack of support for the newly diagnosed*

I would also be concerned about the psychological support, if someone came up positive, about how the GPs would be able to cope with that. Maybe they’d have special training, maybe they already know how to cope with that. But in a sexual health clinic, I’m sure they already have special training.

(Male participant, UK, 24 - MSM)

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Testing as part of the new patient health check

*Negative view*

I definitely wouldn’t have it. (What) I’ve just gone through now I wouldn’t... ... you’re...just registering and it’s like your height, your weight, your….lifestyle and then that’s a bit... I think people would find it invasive (sic).

(Female respondent, UK, 26)
Testing as part of the new patient health check

Positive view

I think it’s a great time. […] As a new patient I think you just want to, you know, get, in a sense, a clean bill of health, a clean slate and, you know, onward with your new GP.

(Male respondent, UK, 54)

INCREASING UPTAKE OF HIV TESTING - II
B.R.I.E.F.: HIV testing in ER in the Bronx

Counsellor offers ER patient multimedia video on laptop

Patient enters own details on lap-top

Oro-quick saliva test
- if negative – video post test counselling
- if positive - counsellor post-test discussion

8257 patients
85% eligible 7109
87% tested 6218
57 new +ves

Y. Calderon et al TUPE0376, CROI 2008

Uptake and outcome of HIV testing in sentinel GUM clinics, UK

Unlinked anonymous surveillance in 16 sentinel genitoaurinary medicine clinics
Uptake and outcome of HIV testing in sentinel GUM clinics, UK

Unlinked anonymous surveillance in 16 sentinel genitourinary medicine clinics

Routine offer of HIV test introduced

Heterosexual men & women

MSM
## Glasgow & Edinburgh: Gay Men’s Sexual Health Surveys 1996 – 2005

### Year

<table>
<thead>
<tr>
<th>Year</th>
<th>1996</th>
<th>1999</th>
<th>2000</th>
<th>2002&lt;sup&gt;a&lt;/sup&gt;</th>
<th>2002&lt;sup&gt;b&lt;/sup&gt;</th>
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<tbody>
<tr>
<td>N</td>
<td>2205</td>
<td>2290</td>
<td>747</td>
<td>1574</td>
<td>278</td>
<td>259</td>
<td>1629</td>
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### Ever had HIV test

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
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<th>n</th>
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<th>n</th>
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<tbody>
<tr>
<td>Total</td>
<td>1119</td>
<td>50.7</td>
<td>1146</td>
<td>50.0</td>
<td>411</td>
<td>55.0</td>
<td>843</td>
<td>53.6</td>
<td>174</td>
<td>62.6</td>
<td>189</td>
<td>73.0</td>
<td>984</td>
<td>60.4</td>
</tr>
<tr>
<td>AOR&lt;sup&gt;*&lt;/sup&gt; of ever had</td>
<td>1</td>
<td>0.98</td>
<td>1.22</td>
<td>1.17</td>
<td>1.73</td>
<td>2.64</td>
<td>1.55</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV test (95% CI)</td>
<td>(0.87-1.10)</td>
<td>(1.03-1.45)</td>
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*Odds ratio of ever having had an HIV test by year of survey, adjusted for age

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### Ever had HIV test

|          | n | %  | n | %  | n | %  | n | %  | n | %  | n | %  |
|----------|---|----|---|----|---|----|---|----|---|----|---|----|---|----|
| Total    | 1119 | 50.7 | 1146 | 50.0 | 411 | 55.0 | 843 | 53.6 | 174 | 62.6 | 189 | 73.0 | 984 | 60.4 |
| AOR<sup>*</sup> of ever had | 1 | 0.98 | 1.22 | 1.17 | 1.73 | 2.64 | 1.55 |
| HIV test (95% CI) | (0.87-1.10) | (1.03-1.45) | (1.03-1.34) | (1.33-2.25) | (1.97-3.52) | (1.36-1.77) |

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Antenatal testing: Normalising Uptake

Uptake of antenatal HIV testing

Control: 6%
Opt-in: 35%
Opt-out: 88%

[UCLH Antenatal Clinic 2008: Average uptake 96-99%]

Uptake and acceptability of antenatal HIV testing: randomised controlled trial of different methods of offering the test

Antenatal HIV testing: assessment of a routine voluntary approach
CONCLUSIONS

- People fearful of an HIV positive diagnosis
  - Stigma
  - Negative consequences

- Normalisation/routine offer of test increases uptake

- Urgent need to reduce undiagnosed fraction
  - Reduce late presentation (and poorer prognosis)


Data on pregnancy status only from 2000
CONCLUSIONS

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