

HIV testing: increasing uptake among people who may have undiagnosed HIV

Evidence review on:

Factors which help or hinder HIV testing among people who may have undiagnosed HIV

Internal Guideline Development Team:

Chris Carmona (Senior Technical Analyst), Diana O'Rourke (Technical Analyst), Stephen Robinson (Assistant Technical Analyst)

December 2015

National Institute for Health and Care Excellence

Table of contents

1.	Introduction.....	3
2.	Methods.....	3
2.1	Review question.....	3
2.2	Searching, screening, quality assessment and data extraction.....	3
3.	Results.....	4
3.1	Flow of literature through the review.....	4
3.2	Characteristics of the included studies	6
3.3	Study findings.....	6
	Views on opt out testing	7
	Barriers to testing among high risk populations	8
	Point of care testing in community and STI services.....	10
	Home sampling kits for sexually transmitted infections.....	11
4.	Discussion.....	12
4.1	Strengths and limitations of the review	12
4.2	Applicability	12
4.3	Gaps in the evidence.....	12
5.	Included studies.....	13
6.	Appendix 1 Evidence Tables.....	14
7.	Appendix 2 Quality of included studies	24
8.	Appendix 3 Methodology checklist: Qualitative studies.....	25

1. Introduction

In September 2014 it was agreed that NICE's guidelines on HIV testing in black Africans and HIV testing in men who have sex with men (MSM) (PH33 and PH34) should be partially updated and combined into one piece of guidance to take account of new evidence relating to indicator conditions, changes in the law relating to home testing and self-sampling, and to reflect changes in commissioning responsibilities for HIV testing. It was agreed that the partial update would combine the recommendations in PH33 and PH34 into generic recommendations and, where appropriate, make specific recommendations for high risk population groups and consider potential changes to indicator conditions and home testing and sampling.

This evidence review has been conducted to support the update of PH33 and PH34 and will focus on the factors that help or hinder the uptake of HIV testing among people who may have undiagnosed HIV, and how barriers can be overcome. The review will also examine new evidence relating to barriers or facilitators to the uptake of HIV testing among all people who may have undiagnosed HIV. The evidence reviews for PH33 and PH34 will also be considered as part of the overall evidence base.

2. Methods

This review was conducted according to the methods guidance set out in '[Developing NICE guidelines: the manual](#)' (October 2014).

2.1 Review question

Review Question 2: What factors help or hinder the uptake of HIV testing among people who may have undiagnosed HIV, and how can the barriers be overcome?

2.2 Searching, screening, quality assessment and data extraction

A single systematic search of relevant databases and websites was conducted from 1996 (the start date for the searches for PH33 and PH34) to May 2015 to identify relevant evidence for this review (see Appendix 5: Review 1a and 1b).

The [protocols](#) outline the methods for the review, including the search protocols and methods for data screening, quality assessment and synthesis.

All references from the database searches were screened on title and abstract against the criteria set out in the protocols. A random sample of 10% of titles and abstracts was screened by two reviewers independently, with differences resolved by discussion. Agreement at this stage was 93.4%. Full-text screening was carried out by two reviewers independently on 10% of papers. Agreement at this stage was 100%. Reasons for exclusion at full paper stage were recorded (see Appendix 4: Review 1a and 1b).

Any studies which were included in PH33 and PH34 have been excluded from this evidence review. There may be some studies which were excluded by PH33 and PH34 which have been included in this review, for example, those covering the more general population or other at-risk groups.

Each included study was data extracted by one reviewer, with all data checked in detail by a second reviewer. Any differences were resolved by discussion.

Included studies were rated individually to indicate their quality, based on assessment using a checklist. Each included study was assessed by one reviewer and checked by another. Any differences in quality grading were resolved by discussion. The tool used to assess the quality of studies is included in Appendix 3 and a summary of the QA results of all included studies is included in Appendix 2. The quality ratings used were:

- ++ All or most of the checklist criteria have been fulfilled, and where they have not been fulfilled the conclusions are very unlikely to alter.
- + Some of the checklist criteria have been fulfilled, and where they have not been fulfilled, or are not adequately described, the conclusions are unlikely to alter.
- Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

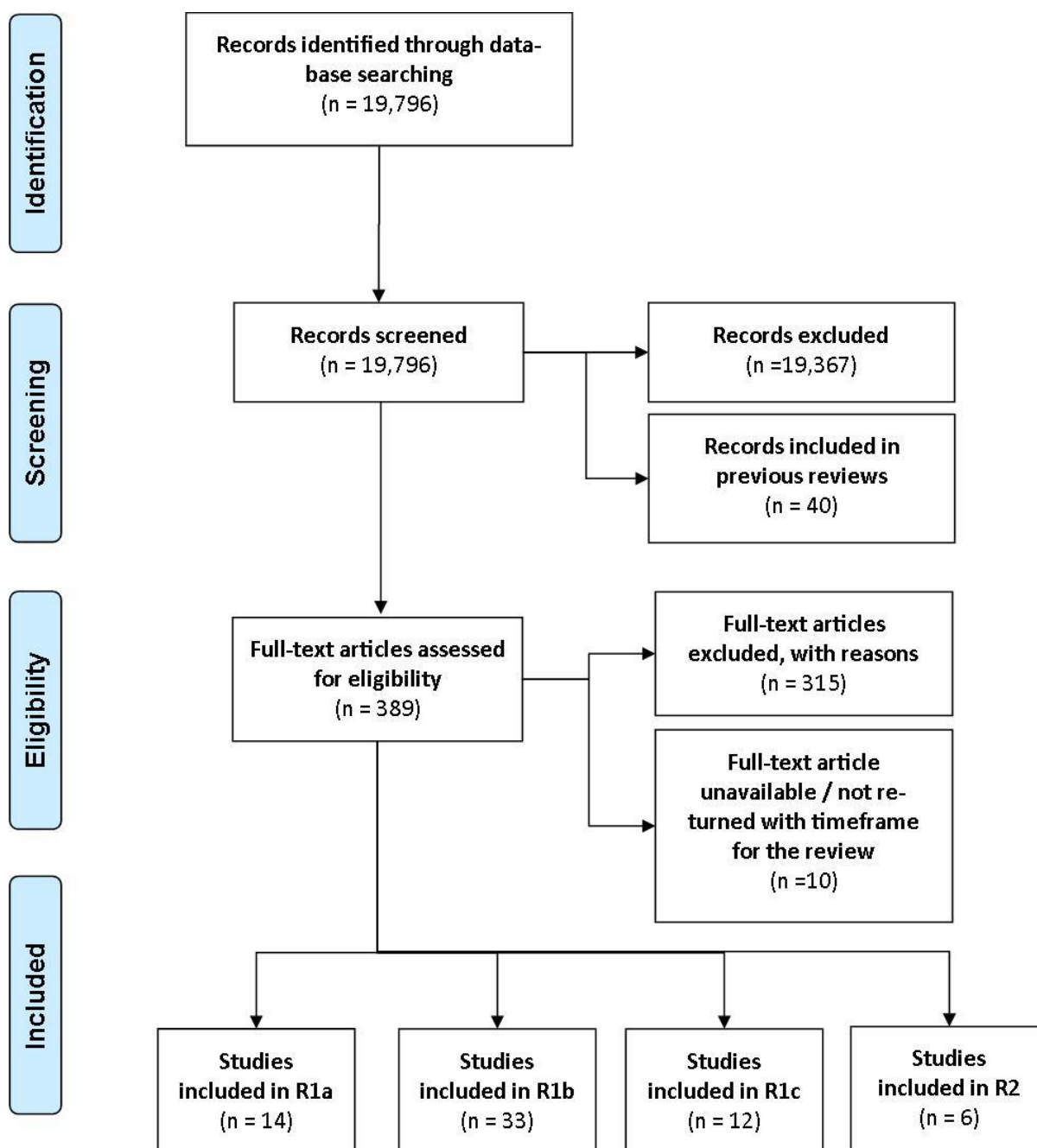
3. Results

3.1 Flow of literature through the review

Six studies were included in review 2. Figure 1 below shows the flow of literature through the review. A brief summary of reasons for exclusion at full text is included in the table below.

Reason	Number
Did not meet the study type criteria	106
Conference abstract	96
Not UK based qualitative study	50
Not about HIV test uptake	20
No specific intervention	15
Outcomes not relevant	14
Out of scope	9
Not English language	3
Other	2

Figure 1. Flow of literature through the review¹
 (note: 1 paper is included in two reviews causing the total to be 390 full text studies)



¹ R1a: What interventions to increase awareness of the benefits of HIV testing and details of local testing services among the general public and healthcare workers are the most effective?
 R1b: What interventions to increase opportunity for, and uptake of, HIV testing are the most effective?
 R1c: What are the most cost effective ways to increase the uptake of HIV testing to reduce undiagnosed HIV among people who may have been exposed to it?
 R2: What factors help or hinder the uptake of HIV testing among people who may have undiagnosed HIV, and how can the barriers be overcome?

3.2 Characteristics of the included studies

Full details of the included studies are given in the evidence tables in [Appendix 1](#). Table 3.2.1 below shows in which country the studies were conducted, and provide a brief summary of the interventions, populations and settings investigated in these studies.

3.2.1. Characteristics of the studies

What factors help or hinder the uptake of HIV testing among people who may have undiagnosed HIV, and how can the barriers be overcome?

First author, year	Design	Country	Setting	Population	Subject	QA rating
Qualitative studies						
Adedimeji et al., 2009	Thematic analysis	Eire	African immigrant communities	Black Africa immigrants	Challenges to testing for immigrants	++
Dowson et al, 2011	Thematic analysis	UK	Hospital outpatients dept,	Men who have sex with men	Reasons for testing late	+
Glew et al., 2014	Framework analysis	UK	Brighton, UK	Mixed (quota based sampling)	Opt out testing	++
MacPherson et al, 2011	Thematic analysis	UK	Community and GU	Providers of HIV POCT	POCT testing programme	+
Pollard et al., 2013	Framework analysis	UK	STI clinic	Volunteers from clinic attendees	Opt out testing	+
Wayal et al, 2011	Framework analysis	UK	Sexual health clinic	MSM	Views on home sampling	+

3.3 Study findings

6 studies were included in the review. Overall, the quality of the studies was good, with 2 of the studies graded [++] and 4 studies graded [+] (see Table 3.2.1). All of the studies were conducted in the UK and Ireland to ensure that they were culturally and contextually appropriate.

Studies were grouped into the following categories:

- Views on opt out testing

- Barriers to testing among high risk populations
- Point of care testing in community and STI services
- Home sampling kits for sexually transmitted infections

Views on opt out testing

Two studies (Glew et al 2014 [++] and Pollard et al 2013 [+]) investigated views on opt-out testing in different populations.

Glew et al (2014 [++]) conducted 9 distinct focus groups with people with a variety of HIV testing experiences as follows:

Focus group	Composition	Group members, n	Mean age, years (range)
1	Younger heterosexual men, negative/untested (≤ 24 years)	5	22 (19–24)
2	Older heterosexual men, negative/untested (≥ 25 years)	6	31 (25–43)
3	Younger heterosexual women, negative/untested (≤ 24 years)	6	21 (18–24)
4	Older heterosexual women, negative/untested (≥ 25 years)	9	44 (27–58)
5	Younger MSM, tested HIV negative (≤ 24 years)	5	21 (19–24)
6	Older MSM, tested HIV negative (≥ 25 years)	5	37 (31–51)
7	Younger MSM, untested (≤ 24 years)	4	17 (17)
8	Black African men, negative/untested	9	30 (23–41)
9	Black African women, tested HIV positive	5	37 (32–47)
	Total	54	28.9 (17–58)

Data were analysed using a framework analysis method.

Key themes were:

- ***Opt-out testing is acceptable***

All groups regarded opt-out HIV testing affirmatively; individual and public benefits to diagnosis and treatment were identified. The main barriers to testing were expectation of a negative result (therefore, the test might be considered unnecessary), and the potential for a positive result (especially among higher prevalence groups).

- ***Appropriate circumstances of opt-out offer: location and timing***

Testing at GP registration was considered appropriate and acceptable overall, however, younger participants in particular raised confidentiality concerns around testing in a family GP; Acute hospital admission was felt a less appropriate setting for an HIV test. Higher prevalence groups (MSM and black African) were most concerned about this, reflecting their awareness of a test's greater potential for a life-changing outcome, and their desire for time to consider testing.

- ***Clinicians' pressure to test***

Several participants (particularly in higher prevalence groups) expressed concern that doctors' status and authority could pressurise people to test against their will. Any perceived pressure to test was considered a factor that would discourage acceptance of the test.

- **Social pressure to test**

Several members of groups in which the prevalence of HIV is low articulated a social pressure for those who had been at risk to test, and considered declining a test selfish.

- **Inferred judgement from clinicians**

Groups in which HIV prevalence is high, and some younger groups, inferred feeling specifically targeted due to their sexuality or race, or that they were being judged for their sexual practices.

- **Normalisation and the universal offer**

An explanation of the universal offer and the opportunity to opt out were felt to increase the likelihood of acceptance in particular implementing the strategy for all eligible persons to prevent high prevalence groups feeling targeted was emphasised.

Pollard et al (2013 [+]) planned 10 focus groups with participants aged over 16 who had tested for an STI in the previous 24 months, using quota sampling based on age, sexuality and gender. However the issue of opt-out testing as a key theme only emerged part way through the process meaning that only 5 focus groups had relevant data (heterosexual women (n=7), heterosexual men (n=7), overseas students (n=5), MSM with HIV (n=6) and lesbian and bi women (n=6)). Participants spoke about HIV testing as part of a package of care with routine testing for STIs in general, asserted their right to opt-out, speculated on the motivations of non-testers and spoke of testing as a moral responsibility. There were high levels of approval and acceptance for opt out HIV testing on registration with a GP and at hospital admission. It was also felt that this could help to 'normalise' the test. There was some concern however that testing could potentially become compulsory in the future.

Evidence statement 1: Opt out testing

There is strong evidence from 2 qualitative UK studies [++; +]^{1,2} that opt out testing is acceptable, particularly at registration with a GP, and to a lesser degree, at hospital admission. Opt-out testing would be normalised by this and may help people not to feel judged or specifically targeted for their sexual practices or race. However, there was concern that doctors may pressurise people to test.

Applicability: The evidence is directly applicable because both studies were undertaken in the UK.

1. Glew et al 2014 [++]
2. Pollard et al 2013 [+]

Barriers to testing among high risk populations

Two studies by Adedimeji et al (2009 [++]) and Dowson et al (2011 [+]) looked at the barriers to testing and the reasons for delaying testing among black African immigrants in the Republic of Ireland, and MSM in Brighton, respectively.

Adedimeji et al. (2009 [++]) used snowball and convenience sampling to recruit 6 focus groups (2 male, 2 female and 2 mixed) and 4 interviews with opinion leaders (2 male, 2 female) in African immigrant communities in County Dublin and County Meath. A total of 60 respondents participated. All were first generation immigrants aged 18–64 years with a mean of 4.7 years since migrating to Ireland. The study identified two major themes: barriers to accessing and utilising services; and negative perceptions and attitudes toward testing.

- **Barriers to accessing and utilising services**

The cost of healthcare (in the Republic of Ireland) was one of the most frequently reported barriers by participants, along with the location and organisation of services, with many immigrants being unaware of private services and believing that hospitals do not offer privacy for those seeking testing. They also described how delays in accessing services and poor provider–patient relationships discourage them from seeking healthcare from hospitals, and mentioned arrogant providers who are insensitive to the needs of immigrants and difficulty in communication due to language limitations of the patient and the unavailability of interpreter services when accessing primary care.

- **Negative Perceptions and Attitudes that Discourage HIV Testing**

There is a strong perception among participants that HIV is still regarded by many as a disease of “people from Africa”, thus creating an atmosphere of mistrust and suspicion in the immigrant community. Participants described experiences of stigma from “very ignorant doctors who think everyone from Africa is living with HIV”. There is strong suspicion that health workers are required to report those with positive status to immigration authorities who may then initiate a deportation process. Apathy towards voluntary HIV testing is intensified by the perceived lack of support from social networks. The consensus is that in dealing with the problem of HIV among immigrants, religious leaders and community leaders should be doing a lot more than they are currently.

Dowson et al. (2011 [+]) recruited 17 MSM who were diagnosed in the last 12 months with a CD4<200 or an Aids defining illness in Brighton. Using a framework analysis approach they identified 4 main themes.

- **Psychological barriers**

Most MSM had a negative perception of HIV. Fear of HIV, becoming ill and dying was a reason often given for not testing. Many still believed HIV was a death sentence.

- **Stigma**

Participants feared telling friends and family about a positive result, and also were afraid of the repercussions of taking a test if it became common knowledge. Fear of stigma from society in general was also an issue.

- **Perceived low risk**

More than half of the men interviewed were surprised by their diagnosis due to perceiving themselves as being safe or predominantly so. They also believed that a lack of symptoms meant they did not have HIV.

- **Barriers in healthcare**

A universal theme was that a more proactive approach by GPs would be beneficial in increasing testing for HIV. The majority agreed they would have tested if it had been offered to them by their GP, although several men admitted declining a test in the past. They felt they would rather test at the GP than the STI clinic.

Evidence statement 2: Barriers to testing among high risk populations

There is strong evidence from 2 qualitative studies, 1 UK [+]¹, 1 ROI [++]², that stigma, fear of judgment and the organisation of services are significant barriers to the uptake of testing in MSM and black African immigrants. Testing in primary care would be a significant step in reducing these barriers.

Applicability: The evidence is directly applicable because both studies were undertaken in the UK.

1. Dowson et al., 2011 [+]
2. Adedimeji et al., 2009 [++]

Point of care testing in community and STI services

One study by MacPherson et al (2011) [+] conducted a multi methods evaluation of a POCT testing scheme in the NE of the UK. Only the qualitative component is reported here. The 25 service providers performing HIV POCT participated in three focus groups (two with providers from community sites and one with providers from the GUM site). All interviews were recorded and transcribed. A framework approach to analysis was undertaken.

POCT providers working within community-based sites highlighted the benefits of reaching out into the community to increase awareness of POCT for HIV and engaging individuals who may have otherwise not been able to access health services, however, service providers felt there was a careful line to tread between supporting someone in a marginalised and vulnerable position to learn their HIV status and placing undue pressure on an individual who had not planned to take an HIV test.

Service providers within the STI clinic highlighted the usefulness of POCT for victims of sexual assault who were about to receive post-exposure prophylaxis. They felt confident offering clients negative results, and facilitating rapid reassurance for individuals suffering traumatic experiences. They also acknowledged the benefits of being able to give a rapid result and not worrying about clients failing to return to collect results.

Evidence statement 3: Point of care testing in community and STI services

Moderate evidence from 1 qualitative study [+]¹ suggests that providers believe that community and GUM clinic-based POCT for HIV was feasible and acceptable to clients and service providers in a low prevalence setting. It successfully reached target groups, many of whom would not have otherwise tested. They believe POCT may be an effective strategy to increase the uptake of HIV testing among groups who are currently underserved.

Applicability: The evidence is directly applicable because the study was undertaken in the UK.

1. MacPherson et al, 2011 [+]

Home sampling kits for sexually transmitted infections

One study by Wayal et al (2011) [+] explored MSM views of home sampling for STI and HIV. They conducted semi structured interviews with 24 purposively selected men who have sex with men from different age groups – six from each age group (<29, 30–39, 40–49, >50) to ensure a wide diversity of ages, from a sample who had previously indicated willingness to be interviewed. The interviews were analysed using a framework analysis approach.

They reported 4 major themes:

- **Venues for accessing home sampling kits.**

Medical venues like STI clinics, doctors surgeries or pharmacies were perceived as 'discreet' and appropriate whereas home sampling kits in gay social venues were less well liked. Participants perceived social spaces to be linked with 'fun', 'relaxation' and 'sex'. Some participants expressed anger at being constantly reminded about STIs and HIV in such venues and did not welcome the provision of home sampling kits in these places. Several participants compared picking up a home sampling kit from commercial outlets to buying condoms, lubricants or pregnancy tests. With time, embarrassment with buying home sampling kits from commercial outlets may reduce. Pharmacies were preferred over generic outlets such as supermarkets. Among young and middle-aged men, societal homophobia may be a deterrent to purchasing home sampling kits from supermarkets, particularly if women are handling the tills.

- **Returning home collected specimens and getting results.**

Concerns about the unreliability of postal services and fear of specimens getting damaged in the transit swayed some participants in favour of hand delivery to the STI clinic rather than postal return of specimens. For others, the ease and convenience of posting them was appealing. Participants linked waiting for test results with anxiety. Overall, the majority of participants expressed preference for having multiple options to receive their results, i.e. phone calls, text messages, emails or post.

- **Testing for STI/HIV using home sampling kits.**

Participants' risk perceptions and health beliefs appeared to influence their sexual health testing behaviour. Sexual health testing was done for peace of mind, to avoid unknowingly infecting others and to seek timely treatment if diagnosed with infections.

- **Clinic use and home sampling kits.**

Home sampling kits were favoured by the majority of the participants for regular asymptomatic sexual health testing. However, participants expressed a preference to access a STI clinic instead of home sampling kits if they had symptoms, were exposed to infection or a sexual partner was diagnosed positive. Some participants expressed a preference to continue testing at STI clinics because of concerns about the accuracy of tests, to divorce STI testing from their home environment or because they were worried about the lack of opportunity to discuss their concerns with health professionals.

Evidence statement 4: Home sampling kits for sexually transmitted infections

Moderate evidence from 1 qualitative UK [+] study¹ examines views on home testing for STI and HIV. It presents evidence that accessing home sampling kits from medical venues rather than gay social venues or commercial venues is preferred due to privacy concerns and fear of being ridiculed by peers. Views about using home sampling kits for HIV testing were mixed. They were viewed as an adjunct to clinics, but clinic attendance was preferred if symptomatic.

Applicability: The evidence is directly applicable because both studies were undertaken in the UK.

1. Wayal et al. 2011 [+]

4. Discussion

4.1 Strengths and limitations of the review

Overall, the quality of the studies was good. (2 studies graded ++, 4 studies graded +)

Some limitations are seen across the studies particularly relating to study design as participants were already users of sexual health services. Further detail on the strengths and weaknesses of individual studies can be found in the evidence tables (Appendix 4)

4.2 Applicability

All of the studies were from the United Kingdom except one that was from Ireland. The Irish study was included because of the strong cultural match with the UK.

4.3 Gaps in the evidence

The following outcomes related to views and barriers about HIV testing were set out in the scope document:

- Awareness of how people who may have undiagnosed HIV view testing and how they think the barriers to testing can be overcome.
- Attitude towards HIV testing among people who may have undiagnosed HIV and service providers (that is, whether or not there is any stigma associated with HIV tests).
- Barriers to HIV testing for people who may have undiagnosed HIV (for example, people who do not speak English as a first language) and service providers

To a greater or lesser extent, all of these questions are addressed within the included qualitative literature, however further data would have allowed more robust evidence statements.

5. Included studies

1. Adedimeji, Adebola A., Asibon, Aba, O'Connor, Gerard, Carson, Richard, Cowan, Ethan, McKinley, Philip, Leider, Jason, Mallon, Patrick, Calderon, Yvette, Increasing HIV testing among African immigrants in Ireland: challenges and opportunities, *Journal of immigrant and minority health / Center for Minority Public Health*, 17, 89-95, 2015
2. Dowson, Lucy, Kober, Catherine, Perry, Nicky, Fisher, Martin, Richardson, Daniel, Why some MSM present late for HIV testing: a qualitative analysis, *AIDS care*, 24, 204-209, 2011
3. Glew, Simon, Pollard, Alex, Hughes, Leila, Llewellyn, Carrie, Public attitudes towards opt-out testing for HIV in primary care: a qualitative study, *The British journal of general practice : the journal of the Royal College of General Practitioners*, 64, e60-6, 2014
4. MacPherson, Peter, Chawla, Anu, Jones, Kathy, Coffey, Emer, Spaine, Vida, Harrison, Ian, Jelliman, Pauline, Phillips-Howard, Penelope, Beynon, Caryl, Taegtmeier, Miriam, Feasibility and acceptability of point of care HIV testing in community outreach and GUM drop-in services in the North West of England: a programmatic evaluation, *BMC public health*, 11, 419, 2011
5. Pollard, A., Llewellyn, C., Smith, H., Richardson, D., Fisher, M., Opt-out testing for HIV: perspectives from a high prevalence community in south-east England, UK, *International journal of STD & AIDS*, 24, 307-12, 2013
6. Wayal, Sonali, Llewellyn, Carrie, Smith, Helen, Fisher, Martin, Alexander, Benn Bloomfield Dodds Huebner Kuo Lambert Lampinen Lister Llewellyn Low Mimiaga Osmond Pai Papp Prost Ritchie Ritchie Spielberg Wayal Young, Home sampling kits for sexually transmitted infections: Preferences and concerns of men who have sex with men, *Culture, health & sexuality*, 13, 343-353, 2011

6. Appendix 1 Evidence Tables

What factors help or hinder the uptake of HIV testing among people who may have undiagnosed HIV, and how can the barriers be overcome?

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
<p>Full citation Adedimeji, Adebola A., Asibon, Aba, O'Connor, Gerard, Carson, Richard, Cowan, Ethan, McKinley, Philip, Leider, Jason, Mallon, Patrick, Calderon, Yvette, Increasing HIV testing among African immigrants in Ireland: challenges and opportunities, Journal of immigrant and minority health / Center for Minority Public Health, 17, 89-95, 2015</p> <p>Quality score ++</p> <p>Study type Qualitative</p> <p>Aim of the study To explore challenges to voluntary HIV-testing for African immigrants in Ireland.</p> <p>Location and setting African immigrant communities in County Dublin and County Meath, Republic of Ireland.</p> <p>Source of funding Albert Einstein College of Medicine Center for Global Health Micro and Pilot Grants in 2011 and 2013.</p>	<p>Data collection utilized snowball and convenience sampling to select participants for a total of 6 focus groups consisting of two male groups, two female groups and two mixed-gender groups. There were 8 participants in single gender groups and 12 participants in mixed gender groups. In addition, individual interviews were held with two male and two female opinion leaders selected by snowball techniques. Data was obtained using a semi-structured interview guide that allowed facilitators flexibility to consider other issues that emerged during the interview.</p> <p>Method of analysis All interviews conducted in English were transcribed and scrutinized for consistency with the digital recordings. Authors reviewed the transcripts several</p>	<p>Inclusion criteria Black African immigrants >18 years, lived in Ireland for at least 2 years, communicate in English and not previously diagnosed with HIV.</p>	<p>Number of participants 60</p> <p>Participant characteristics All were first generation immigrants aged 18–64 years with a mean of 4.7 years since migrating to Ireland. One-third of participants have postgraduate diplomas and the rest are currently studying in Irish colleges and universities. Two-thirds were employed or self-employed while the rest receive social welfare/unemployment assistance from the government through the asylum system. Ten participants in the refugees/asylum system were previously offered HIV testing. None tested positive.</p>	<p>Key themes <u>Barriers to Accessing and Utilizing Health Services</u> Cost, Location and Organisation of Services - The cost of healthcare was one of the most frequently reported barriers by participants. <i>"It is difficult to come up with 40 or 50 euros just to see the doctor...most people are unwilling to pay the money because of other commitments. To get an HIV test from the doctor means you will have to pay this money and this is the reason many immigrants are not accessing health care"</i>. The location and organization of HIV testing and treatment services was also reported as another constraint for immigrants seeking access to testing services. Location of testing facilities in hospitals and lack of awareness of private facilities hinder access to HIV testing. Many immigrants believe hospitals do not offer privacy for those seeking confidential testing. <i>"There's only one or two clinics where you can go to get tested and there's no privacy at all because it is the place where everyone in need of HIV testing goes no matter how sick they are. Once you are there, everyone automatically knows what you are there for"</i>. Delay in Accessing Services - Waiting times in government funded health facilities result in delayed/late diagnosis, missed opportunities for prevention/early detection and linkage to care, and is a major factor in poor health-seeking behavior among immigrants. <i>"Many immigrants prefer to self-medicate, you know, instead of going through the trouble of accessing the Irish health system. When it comes to seeing a consultant or specialist, the process is so long that sometimes you are better off doing something on your own than being put on a wait list for 9</i></p>	<p>Limitations identified by author None reported</p>

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
	<p>times to become familiar with the content before editing, coding and identifying themes. Data analysis followed a thematic framework in which themes were identified through an inductive and deductive process. Thereafter, codes from the transcripts were assigned to relevant themes to facilitate interpretation and reporting based on the study's aims.</p>			<p><i>months or being asked to provide all kinds of documentation you don't have".</i> Provider/patient relationship - poor provider-patient relationships discourage them from seeking healthcare. <i>"Sometimes when you go to the Irish doctor, he's already judged you because you are black and gives you little opportunity to explain how you see things. Because of ignorance or arrogance, some doctors will tell you they know better than you. If I encounter a black doctor who is talking about HIV, I would be more inclined to listen because he's less likely to be biased since we are from the same continent"</i> <u>Negative Perceptions and Attitudes that Discourage HIV Testing</u> Perceived and Experienced Stigma - Ignorance, stigma and negative attitudes continue to prevent African immigrants in Ireland from seeking or accepting routine HIV testing services or accessing care/treatment. <i>"... It is unfortunate that HIV and AIDS is associated with black people maybe because of our low socioeconomic status, you know that we are poor..."</i>. There is strong suspicion that health workers are required to report those with positive status to immigration authorities who may then initiate a deportation process. Perceived Discriminatory Policies - Participants described their angst about discriminatory policies that reinforce stereotypes of Africans as HIV carriers. Reports that routine HIV tests are offered only to black African refugees and asylum seekers, or those seeking to access state funded welfare benefits and certain services from financial institutions were examples of discriminatory practices, which they believed are due to government-backed policies that reinforce perceptions of HIV/AIDS as "primarily a disease of black Africans". Perceived Lack of Support from Religious Leaders and Social Networks - A perceived lack of social support and rapid spread of gossip about a potentially stigmatizing condition makes it unattractive to seek voluntary HIV testing or</p>	

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
				<p>disclose seropositive status. Negative reactions from the wider social network and lack of trust for religious leaders were also reported as key concerns among those who may be contemplating an HIV test. <i>"Pastors are not to be trusted with such details. To be fair, they will not mention the name of the person, but by the time they include anecdotes about your situation in their sermon notes, it is clear to everyone who they are talking about"</i></p> <p>Religious leaders were accused of neglecting an important issue facing immigrants and the consensus is that in dealing with the problem of HIV among immigrants, religious leaders and community leaders should be doing a lot more than they are currently are.</p>	
<p>Full citation Dowson, Lucy, Kober, Catherine, Perry, Nicky, Fisher, Martin, Richardson, Daniel, Why some MSM present late for HIV testing: a qualitative analysis, AIDS care, 24, 204-209, 2011</p> <p>Quality score +</p> <p>Study type Qualitative</p> <p>Aim of the study To explore why testing was not carried out earlier in MSM with a late diagnosis of HIV.</p> <p>Location and setting Outpatients department of UK hospital.</p> <p>Source of funding None reported</p>	<p>Data collection Semi-structured interviews</p> <p>Method of analysis Thematic analysis</p>	<p>Inclusion criteria</p> <ul style="list-style-type: none"> • MSM • CD4 <200 or an Aids defining illness • Diagnosed in last 12 months 	<p>Number of participants 17 participants</p> <p>Participant characteristics Aged 33 - 67 Men who have sex with men</p>	<p>Key themes</p> <p>Four key themes were identified: <u>Psychological barriers</u> - Negative perceptions of HIV, fear of becoming ill and dying from Aids. <i>"...its the fear of dying I think ... I was scared, very scared before I found out". "I didnt know much about it at all. I just thought it was a death sentence and I suppose yeah, I've just always thought of it a little like that, even last year when i was diagnosed"</i>.</p> <p><u>Stigma of HIV</u> - Fear of telling friends and family. Fear of a positive diagnosis becoming common knowledge. <i>"It was quite taboo...going to get things like an HIV test". "Well if you do test positive...then you have to count yourself as belonging to a group that maybe isnt regarded very highly in society"</i>.</p> <p><u>Perceived low risk</u> - Participants were surprised by their diagnosis due to perceiving themselves as being low risk and only practising safe sex or having low risk activities. <i>"I thought it can't possibly happen to me because I'm not doing all these high risk things". "There was I suppose a little bit of frustration because as i say I haven't been excessively sexually active over the previous 4 years"</i>.</p> <p><u>Barriers in healthcare</u> - A universal theme was</p>	<p>Limitations identified by author None identified</p> <p>Limitations identified by review team</p> <p>Other comments No funding details unknown whether there is any conflict</p>

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes																																																						
				that a more proactive approach (by health professionals) would be beneficial in increasing testing for HIV.																																																							
<p>Full citation Glew, Simon, Pollard, Alex, Hughes, Leila, Llewellyn, Carrie, Public attitudes towards opt-out testing for HIV in primary care: a qualitative study, The British journal of general practice : the journal of the Royal College of General Practitioners, 64, e60-6, 2014</p> <p>Quality score ++</p> <p>Study type Qualitative</p> <p>Aim of the study To further understand the public's perspective on opt-out testing for HIV in England.</p> <p>Location and setting Participants were recruited through email or letters to community organisations, and via a classified advertising website. Brighton, England</p> <p>Source of funding The British Academy for the Humanities and Social Sciences BRITAC Small Grants Fund (SG101434).</p>	<p>Data collection Focus groups - composition [number of ppts] 1 Younger heterosexual men, negative/untested (≤24 years) [5] 2 Older heterosexual men, negative/untested (≥25 years) [6] 3 Younger heterosexual women, negative/untested (≤24 years) [6] 4 Older heterosexual women, negative/untested (≥25 years) [9] 5 Younger MSM, tested HIV negative (≤24 years) [5] 6 Older MSM, tested HIV negative (≥25 years) [5] 7 Younger MSM, untested (≤24 years) [4] 8 Black African men, negative/untested [9] 9 Black African women, tested HIV positive [5]</p> <p>Method of analysis Framework analysis</p>	<p>Inclusion criteria Nine distinct groups of people with a variety of HIV-testing experiences were recruited using a quota sampling framework based on sexual orientation, age, sex, and ethnicity.</p>	<p>Number of participants 54</p> <p>Participant characteristics</p> <table border="1"> <thead> <tr> <th>Demographic</th> <th>Participants</th> </tr> </thead> <tbody> <tr> <td colspan="2">Age, years</td> </tr> <tr> <td>Range</td> <td>17–58</td> </tr> <tr> <td>Average</td> <td>28.9</td> </tr> <tr> <td colspan="2">Sexuality</td> </tr> <tr> <td>Heterosexual</td> <td>38</td> </tr> <tr> <td>Homosexual/bisexual</td> <td>14</td> </tr> <tr> <td>Not reported</td> <td>2</td> </tr> <tr> <td colspan="2">Sex</td> </tr> <tr> <td>Male</td> <td>34</td> </tr> <tr> <td>Female</td> <td>20</td> </tr> <tr> <td colspan="2">Ethnicity</td> </tr> <tr> <td>White British</td> <td>28</td> </tr> <tr> <td>White other</td> <td>4</td> </tr> <tr> <td>Black African</td> <td>14</td> </tr> <tr> <td>Hispanic</td> <td>1</td> </tr> <tr> <td>Mixed</td> <td>2</td> </tr> <tr> <td>Other</td> <td>2</td> </tr> <tr> <td>Not reported</td> <td>3</td> </tr> <tr> <td colspan="2">HIV status</td> </tr> <tr> <td>Negative/untested</td> <td>49</td> </tr> <tr> <td>Positive</td> <td>5</td> </tr> <tr> <td colspan="2">HIV testing history</td> </tr> <tr> <td>Tested</td> <td>35</td> </tr> <tr> <td>Never tested</td> <td>19</td> </tr> <tr> <td colspan="2">Last test location</td> </tr> <tr> <td>General practice</td> <td>3</td> </tr> </tbody> </table>	Demographic	Participants	Age, years		Range	17–58	Average	28.9	Sexuality		Heterosexual	38	Homosexual/bisexual	14	Not reported	2	Sex		Male	34	Female	20	Ethnicity		White British	28	White other	4	Black African	14	Hispanic	1	Mixed	2	Other	2	Not reported	3	HIV status		Negative/untested	49	Positive	5	HIV testing history		Tested	35	Never tested	19	Last test location		General practice	3	<p>Key themes Opt-out testing is acceptable All groups regarded opt-out HIV testing affirmatively; individual and public benefits to diagnosis and treatment were identified. The main barriers to testing were expectation of a negative result (therefore, the test might be considered unnecessary), and the potential for a positive result (especially among higher prevalence groups). The documentation of testing within medical records and its potential impact on future financial applications was also a concern. <i>"The only problem with getting it done at the doctors is it's not anonymous so if you then want to get health insurance in later years you have to admit having the test which will make your premiums go up possibly"</i>.</p> <p>Appropriate circumstances of opt-out offer: location and timing Testing at GP registration was considered appropriate and acceptable overall, however, younger participants in particular raised confidentiality concerns around testing at a family GP: <i>'I would be worrying if my mum or dad found out because they have the same GP as me, so I'd be like, "What if they find out? What are they going to think of me?"'</i> Acute hospital admission was felt a less appropriate setting for an HIV test. Higher prevalence groups (MSM and black African) were most concerned about this, reflecting their awareness of a test's greater potential for a life-changing outcome, and their desire for time to consider testing: <i>'I don't think it would be wise for you to offer HIV tests to someone who comes into the hospital for another thing [...]. He himself should be prepared psychologically.'</i></p> <p>Clinicians' pressure to test</p>	<p>Limitations identified by author A limitation of the study was the failure to recruit MSM ≥25 years old who had never tested for HIV. Recruitment failure meant that it was not possible to obtain the views of certain groups that would have been beneficial to obtain including black African women who were HIV negative or had never tested</p>
Demographic	Participants																																																										
Age, years																																																											
Range	17–58																																																										
Average	28.9																																																										
Sexuality																																																											
Heterosexual	38																																																										
Homosexual/bisexual	14																																																										
Not reported	2																																																										
Sex																																																											
Male	34																																																										
Female	20																																																										
Ethnicity																																																											
White British	28																																																										
White other	4																																																										
Black African	14																																																										
Hispanic	1																																																										
Mixed	2																																																										
Other	2																																																										
Not reported	3																																																										
HIV status																																																											
Negative/untested	49																																																										
Positive	5																																																										
HIV testing history																																																											
Tested	35																																																										
Never tested	19																																																										
Last test location																																																											
General practice	3																																																										

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes																										
			<table border="1"> <tr> <td>GUM/hospital</td> <td>17</td> </tr> <tr> <td>Community service</td> <td>3</td> </tr> <tr> <td>Not reported</td> <td>31</td> </tr> <tr> <td colspan="2">Employment status</td> </tr> <tr> <td>Employed/self-employed</td> <td>17</td> </tr> <tr> <td>Unemployed</td> <td>15</td> </tr> <tr> <td>Full-time education</td> <td>8</td> </tr> <tr> <td>Not reported</td> <td>14</td> </tr> <tr> <td colspan="2">Highest educational qualification</td> </tr> <tr> <td>≤GCSE</td> <td>15</td> </tr> <tr> <td>A' levels/diploma</td> <td>13</td> </tr> <tr> <td>≥Degree</td> <td>18</td> </tr> <tr> <td>Not reported</td> <td>8</td> </tr> </table>	GUM/hospital	17	Community service	3	Not reported	31	Employment status		Employed/self-employed	17	Unemployed	15	Full-time education	8	Not reported	14	Highest educational qualification		≤GCSE	15	A' levels/diploma	13	≥Degree	18	Not reported	8	<p>Several participants (particularly in higher prevalence groups) expressed concern that doctors' status and authority could pressurise people to test against their will: <i>'Doctors, sometimes they have an overwhelming influence for patients so, when somebody of that calibre says go for a test, it's very hard for you to say no to someone who is just trying to help, from his own perspective.'</i> Any perceived pressure to test was considered a factor that would discourage acceptance of the test.</p> <p>Social pressure to test Several members of groups in which the prevalence of HIV is somewhat low articulated a social pressure for those who had been at risk to test, and considered declining a test selfish: <i>'... what if somebody says "Well I don't care, I just don't care about it"? I think that's wrong, that's morally wrong in my eyes.'</i></p> <p>Inferred judgement from clinicians Groups in which HIV prevalence is high, and some younger groups, inferred feeling specifically targeted due to their sexuality or race, or that they were being judged for their sexual practices: <i>'It's a fear of judgement as well [...], a couple of times I've been asked — it just seems like I'm not even talking about that so why do you even bring it up? Are you trying to suggest that I've got something? And, actually, when you talk to them it's just something that they do as standard procedure. That's fine, but you obviously think you're being judged.'</i></p> <p>Normalisation and the universal offer An explanation of the universal offer and the opportunity to opt out were felt to increase the likelihood of acceptance. The importance of implementing the strategy for all eligible persons to prevent high prevalence groups feeling targeted was emphasised: <i>'That's why it's important to make it like a normal thing so they don't feel like they've been picked out.'</i></p>	
GUM/hospital	17																														
Community service	3																														
Not reported	31																														
Employment status																															
Employed/self-employed	17																														
Unemployed	15																														
Full-time education	8																														
Not reported	14																														
Highest educational qualification																															
≤GCSE	15																														
A' levels/diploma	13																														
≥Degree	18																														
Not reported	8																														
Full citation	Data collection	Inclusion criteria	Number of participants	Key themes	Limitations																										

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
<p>MacPherson, Peter, Chawla, Anu, Jones, Kathy, Coffey, Emer, Spaine, Vida, Harrison, Ian, Jelliman, Pauline, Phillips-Howard, Penelope, Beynon, Caryl, Taegtmeier, Miriam, Feasibility and acceptability of point of care HIV testing in community outreach and GUM drop-in services in the North West of England: a programmatic evaluation, BMC public health, 11, 419, 2011</p> <p>Quality score +</p> <p>Study type Mixed methods of research were used incorporating participatory approaches, situational analysis, focus group discussions, analysis of routine patient monitoring data, and analysis of self-completed questionnaires patients recruited for POCT.</p> <p>Aim of the study To evaluate a community and genitourinary medicine (GUM)-based point of care testing (POCT) programme.</p> <p>Location and setting Community and GU settings in Liverpool, UK</p> <p>Source of funding Wellcome Trust Clinical PhD Programme at Liverpool School of Tropical Medicine. Gilead UK and Ireland</p>	<p>Three focus groups (two with providers from community sites and one with providers from the GUM site).</p> <p>Method of analysis Thematic analysis using NVIVO8. Emerging themes were grouped and triangulated with the steering committee members. Transcripts were independently reviewed by a second researcher to confirm themes.</p>	<p>Service provider providing HIV POCT at one of the six sites in the study.</p>	<p>25 Participant characteristics POCT service providers</p>	<p>Community based service providers Health care providers working within community-based sites highlighted the benefits of reaching out into the community to increase awareness of POCT for HIV and engaging individuals who may have otherwise not been able to access health services: <i>“When people come to [the GUM clinic], they already know a certain amount about [HIV] and have thought about it but when we reach out we are tapping out into a whole different community”</i>. They felt that POCT provided a unique opportunity for integrating public health messages: <i>“They were high risk patients that were non-reactive so it was a good opportunity to reinforce behavioural change ... just reinforce the fact that if he is going to have sex outside of his marriage, particular with high risk, then he needs to protect himself because his whole world will just sort of collapse. So it was worth doing it for that”</i>. Challenges included treading a careful line between supporting someone in a marginalised and vulnerable position to learn their HIV status and placing undue pressure on an individual who had not planned to take an HIV test, and communicating with labs for follow up testing and results.</p> <p>Clinic based service providers Service providers within LCSH highlighted the usefulness of POCT for individuals who were victims of sexual assault and who were about to receive post-exposure prophylaxis. They felt confident offering clients negative results, facilitating rapid reassurance for individuals suffering traumatic experiences. They also acknowledged the benefits of being able to give a rapid result and not having to worry about clients failing to return to the department to collect results.</p> <p>Issues identified A common theme for both groups of service providers was their initial concern and confidence in their knowledge of HIV should clients ask difficult questions.</p>	<p>identified by author A recognised limitation of focus group discussions is that group dynamics may lead to over-emphasis of certain themes which, in individual interviews, may not have been particularly important. This effect was limited by structuring groups to include service providers working from teams in similar environments and by using flipchart exercises to focus group discussions.</p> <p>Limitations identified by review team The qualitative focus groups were a small part of a multi component process evaluation and as a result of that the reporting of both methodology and results is brief. This impacts the trustworthiness of the data.</p>

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
fellowship programme paid for salary for one author and funded test kits					
<p>Full citation Pollard, A., Llewellyn, C., Smith, H., Richardson, D., Fisher, M., Opt-out testing for HIV: perspectives from a high prevalence community in south-east England, UK, International journal of STD & AIDS, 24, 307-12, 2013</p> <p>Quality score +</p> <p>Study type Qualitative</p> <p>Aim of the study To explore peoples perspectives and attitudes to opt out testing.</p> <p>Location and setting Users of STI services in Brighton, UK</p> <p>Source of funding NIHR Research for Patient Benefit Programme (PB-PG-0407-13211).</p>	<p>Data collection 10 focus groups were run, data from 5 is included in the study as the 'opt-in' perspective was added to the topic guide when it became clear it was an issue.</p> <p>Method of analysis Framework analysis.</p>	<p>Inclusion criteria Volunteers on a first come first served basis until quotas were filled (age, sexuality, gender, overseas students, HIV positive individuals).</p>	<p>Number of participants 31</p> <p>Participant characteristics Average age 33 (range 16 - 65 years), 15 women, 16 LGB identified.</p>	<p>Key themes</p> <ul style="list-style-type: none"> • High levels of approval and acceptance for being offered opt-out HIV testing on GP registration and at hospital admission. The normalising effect of routine testing was seen to be of positive value. • Would like to be tested for other STIs at the same time. • People from low prevalence groups spoke of testing as a moral obligation for those in high risk groups. <i>"Yeah, I think thats quite a good thing, I mean...it'll force people."</i> • This initial enthusiasm was followed by caution and anxiety about the process of opt out consent, with some people fearing that testing would be compulsory in the future. • The introduction of opt-out testing was contextualised by some people as the starting point for a potentially traumatic and ongoing experience of distress and stigma. <i>"The downside [of increased testing] is all the dirt it's going to throw up as to relationships and all that sort of thing...I think the social aspect of that, of all these people all of a sudden being diagnosed...I think the support has got to be there and thats the important thing..."</i> 	<p>Limitations identified by author Participants in the study were all users of STI services over the previous 2 years. The idea of opt out testing as a theme was introduced half way through the study.</p>
<p>Full citation Wayal, Sonali, Llewellyn, Carrie, Smith, Helen, Fisher, Martin, Alexander, Benn Bloomfield Dodds Huebner Kuo Lambert Lampinen Lister Llewellyn Low Mimiaga</p>	<p>Data collection Semi-structured interviews lasting approx 30 mins (range 12-57 minutes).</p> <p>Method of analysis</p>	<p>Inclusion criteria Men who have sex with men who were aged > 18 years, who tested either negative or positive for pharyngeal and/or rectal Neisseria gonorrhoea</p>	<p>Number of participants 24 (6 from each age group)</p> <p>Participant characteristics Purposively selected men who have sex with men from different age groups (<29, 30–39, 40–</p>	<p>Key themes <u>Venues for accessing home sampling kits.</u> preference for medical venues: Medical venues like STI clinics, doctors surgeries or pharmacies were perceived as 'discreet' and appropriate, <i>"I mean I can't see anywhere [to pick up home sampling kit] really except for a clinic or at advice</i></p>	<p>Limitations identified by author Study participants were users of a sexual health clinic and this is likely to have biased the</p>

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
<p>Osmond Pai Papp Prost Ritchie Ritchie Spielberg Wayal Young, Home sampling kits for sexually transmitted infections: Preferences and concerns of men who have sex with men, Culture, health & sexuality, 13, 343-353, 2011</p> <p>Quality score +</p> <p>Study type Qualitative</p>	<p>Framework analysis</p>	<p>and/or Chlamydia trachomatis during routine clinical testing but were asymptomatic.</p>	<p>49, >50) to ensure a wide diversity of ages, from a sample who had previously indicated willingness to be interviewed.</p>	<p><i>centres, health centres, doctors surgeries, things like that."</i></p> <p>home sampling kits in gay social venues: Perceived to be social spaces linked with 'fun', 'relaxation' and 'sex'. Some participants expressed anger at being constantly reminded about STIs and HIV in such venues and did not welcome the provision of home sampling kits in these places. <i>"I just think you will spend a lot of time and a lot of them will get picked up and thrown about or used as a joke or . . . and not only that there's this thing . . . especially on the gay scene, . . . because people were always sticking buckets in my face or doing things, handing out safe sex packs and things and sometimes my friend when he . . . the guy who died, when he went into a club he didn't want to remember [being HIV positive], he just wanted to go out there and socialise and have a good time."</i></p> <p>Home sampling kits in commercial venues: Several participants compared picking up a home sampling kit from commercial outlets to buying condoms, lubricants or pregnancy tests. With time embarrassment with buying home sampling kits from commercial outlets may reduce. Pharmacies were preferred over generic outlets such as supermarkets. Among young and middle-aged men, societal homophobia may be a deterrent to purchasing home sampling kits from supermarkets, particularly if women are handling the tills. <i>"I think it does kind of depend on how much bottle you've got really and if you're going be embarrassed about it and if this is supposed to sort of get more people to be able to test themselves then you know there's going to be pluses and minuses to it, but if it's out there and people have access to it they're more likely to use it. But it's still this kind of like going to buy condoms or something when you're younger".</i></p> <p>Returning home collected specimens and getting results.</p> <p>Significance of assurance about the receipt of specimens by the clinic: Concerns about the unreliability of postal services and fear of specimens getting damaged in the transit swayed</p>	<p>results in favour of medical venues, their familiarity is reflected in their awareness of the importance of seeking timely care. The majority of our study participants were white British men, reflecting the pre-dominant white population in Brighton.</p> <p>Limitations identified by review team</p> <p>Average interview time is quite short for semi structured interviews. This may influence the trustworthiness and richness of the data.</p>

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
				<p>some participants in favour of hand delivery to the STI clinic rather than postal return of specimens. For others, for others, the inhibition to carry the specimens to the clinic and the ease and convenience of posting them was appealing. <i>“I don’t know. I’d be afraid in case anything got damaged or something. You know, the cases or something not working, which means you’d have to do it again. I think once it’s done, if you carry it to somewhere, to take it straight to the hospital, the chemist or whatever, then that’s everything”.</i></p> <p>Multiple choices for receiving results: Participants linked waiting for test results with anxiety. Overall, the majority of participants expressed preference for having multiple options to receive their results, i.e. phone calls, text messages, emails or post. <i>“Well, you know, I went like a week and a half ago and you think well I’m a week and a half into the three weeks but, you know, and you start sort of thinking well I would have known within the week, but would I . . . maybe they’re busy, all that kind of thing. So you’re still sort of like–still thinking until the end of the three weeks...”.</i></p> <p><u>Testing for STI/HIV using home sampling kits.</u> Participants’ risk perceptions and health beliefs appeared to influence their sexual health testing behaviour. Sexual health testing was done for peace of mind, to avoid unknowingly infecting others and to seek timely treatment if diagnosed with infections.</p> <p><u>Clinic use and home sampling kits.</u> Home sampling kits were favoured by the majority of the participants for regular asymptomatic sexual health testing. However, participants expressed a preference to access a STI clinic instead of home sampling kits if they had symptoms, were exposed to infection or a sexual partner was diagnosed positive. Some participants expressed a preference to continue testing at STI clinics because of concerns about the accuracy of tests, to divorce STI testing from their home environment or because they were worried about the lack of opportunity to discuss their concerns with health professionals. <i>“I think if</i></p>	

Study details	Research parameters	Inclusion / Exclusion criteria	Population	Results	Notes
				<p><i>I had symptoms I would go straight to a clinic because it's obviously something that needs . . . you know medical [intervention] . . .”.</i></p>	

7. Appendix 2 Quality of included studies

	Question														Overall Assessment
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	
Adedimeji, Adebola A., Asibon et al	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Not Sure	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Dowson, Lucy, Kober et al	Appropriate	Clear	Defensible	Appropriately	Not described	Unclear	Unreliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not sure/ not reported	+
Glew, Simon, Pollard et al	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Not sure/not reported	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
MacPherson, Peter, Chawla et al	Appropriate	Mixed	Defensible	Not sure/ Inadequately reported	Not described	Clear	Reliable	Rigorous	Poor	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Pollard, A., Llewellyn, C., Smith, H. et al	Appropriate	Clear	Not sure	Not sure/ Inadequately reported	Not described	Clear	Unreliable	Rigorous	Rich	Not sure/not reported	Convincing	Relevant	Inadequate	Appropriate	+
Wayal, Sonali, Llewellyn et al	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Unreliable	Rigorous	Rich	Reliable	Convincing	Relevant	Inadequate	Appropriate	+

Key to questions:

1. Is a qualitative approach appropriate?
2. Is the study clear in what it seeks to do?
3. How defensible/rigorous is the research design/methodology?
4. How well was the data collection carried out?
5. Is the role of the researcher clearly described?
6. Is the context clearly described?
7. Were the methods reliable?
8. Is the data analysis sufficiently rigorous?
9. Is the data 'rich'?
10. Is the analysis reliable?
11. Are the findings convincing?
12. Are the findings relevant to the aims of the study?
13. Conclusions
14. Ethics

8. Appendix 3 Methodology checklist: Qualitative studies

Study identification <i>Include author, title, reference, year of publication</i>		
Guidance topic:	Key research question/aim:	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? <i>For example,</i> <ul style="list-style-type: none"> • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question? 	Choose an item.	Comments:
2. Is the study clear in what it seeks to do? <i>For example,</i> <ul style="list-style-type: none"> • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed? 	Choose an item.	Comments:
Study Design		

<p>3. How defensible/rigorous is the research design/methodology?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified? 	<p>Choose an item.</p>	<p>Comments:</p>
<p>Data collection</p>		
<p>4. How well was the data collection carried out?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic? 	<p>Choose an item.</p>	<p>Comments:</p>
<p>Trustworthiness</p>		
<p>5. Is the role of the researcher clearly described?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants? 	<p>Choose an item.</p>	<p>Comments:</p>

<p>6. Is the context clearly described?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered 	<p>Choose an item.</p>	<p>Comments:</p>
<p>7. Were the methods reliable?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Was data collected by more than one method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to? 	<p>Choose an item.</p>	<p>Comments:</p>
<p>Analysis</p>		
<p>8. Is the data analysis sufficiently rigorous?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data? 	<p>Choose an item.</p>	<p>Comments:</p>
<p>9. Is the data 'rich'?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been 	<p>Choose an item.</p>	<p>Comments:</p>

<p>explored?</p> <ul style="list-style-type: none"> • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites? 		
<p>10. Is the analysis reliable?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Did more than one researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/ discrepant results addressed or ignored? 	Choose an item.	Comments:
<p>11. Are the findings convincing?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Is the data appropriately referenced? • Is the reporting clear and coherent? 	Choose an item.	Comments:
<p>12. Are the findings relevant to the aims of the study?</p>	Choose an item.	Comments:
<p>13. Conclusions</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • How clear are the links between data, 	Choose an item.	Comments:

<p>interpretation and conclusions?</p> <ul style="list-style-type: none"> • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? • Is there adequate discussion of any limitations encountered? <p>•</p>		
Ethics		
<p>14. How clear and coherent is the reporting of ethics?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour etc? • Was the study approved by an ethics committee? 	Choose an item.	Comments:
Overall Assessment		
<p>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</p>	Choose an item.	Comments: