Community HIV Testing:

Intervention Design Toolkit

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1. Introduction

Community-based HIV testing is a valuable contributor to the effort to end HIV transmissions in England. By drawing on the experience of current community testing providers, this toolkit explores the key questions to consider when designing and delivering community testing interventions in England, and shares learning from across the sector.

For specific guidance on delivering community testing interventions during COVID-19, please see HIV Prevention England's Framework for delivering Community-Based HIV and Sexual Health Services during COVID-19.

1.1 Who is this toolkit for?

- **Community Testing Providers (CTPs):** (Most commonly) voluntary sector organisations that deliver community-based HIV testing interventions. The toolkit also aims to support organisations that don't currently offer testing but are interested in doing so.
- **Commissioners:** In England responsibility for the commissioning of sexual health, including HIV testing, lies predominantly with upper tier local authorities. HIV Prevention England provides additional funding for community testing through national campaigns, and some NHS Trusts subcontract CTPs to deliver HIV testing in the community.
- **Sexual Health Services (SHS):** NHS-led sexual health services (or sexual health clinics) that provide clinical governance to Community Testing Providers. SHS may also conduct outreach HIV testing in community settings.

1.2 What is community testing?

The term 'community testing' is used to describe a diverse range of interventions. For the purpose of this toolkit, we are mainly addressing HIV testing that is:

- Led by community organisations
- Delivered outside of traditional healthcare settings
- Designed to engage specific populations, particularly those at increased risk of HIV who may not be accessing traditional health services
- Accessible and acceptable to the target population/s
- Designed and delivered with the involvement of the target population/s.

We know that there are examples of community-based HIV testing delivered by or in collaboration with NHS providers, for which much of the information here will still be useful and relevant.

1.3 The importance of HIV testing

There has been remarkable progress in reducing HIV diagnoses in the UK in recent years. Since 2015 there has been a sharp decline in diagnoses, and in 2017 the UK was one of the first countries to meet the UNAIDS 90:90:90 targets. According to the most recent data available, 93% of people living with HIV are diagnosed, 97% of people who are diagnosed are receiving treatment, and 97% of people on treatment are virally suppressed – and therefore unable to pass on HIV.[1]

HIV testing has been central to this progress and remains so for a number of reasons:

Testing prevents further transmission

1 in 14 people living with HIV in the UK are still unaware of their status.[2] Testing and diagnosing this group is key to ending HIV transmissions because:

1. People on effective treatment cannot pass on HIV.[3] When an individual is diagnosed they can immediately begin antiretroviral therapy (ART). Once ART reduces their viral load to an 'undetectable' level they are unable to transmit the virus to others (**Undetectable = Untransmittable**).
2. People tend to adapt sexual behaviours to reduce risk immediately following diagnosis.[4]

1 Public Health England (PHE), 2019, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030, 2019 report* [https://www.gov.uk/government/publications/hiv-in-the-united-kingdom]
2 *Ibid.*
3 See British HIV Association's (BHIVA) position statement on U=U, November 2018 [https://www.bhiva.org/BHIVA-encourages-universal-promotion-of-U-U]
4 PHE, 2014, *Addressing Late HIV Diagnosis through Screening and Testing: An Evidence Summary* [https://www.gov.uk/guidance/hiv-testing]

Modelling in 2010 showed that 82% of transmissions amongst MSM (gay, bisexual and other men who have sex with men) in the UK were from those who were undiagnosed.[5] Clinical guidelines have since changed so that people are immediately prescribed ART following diagnosis. This means that the proportion of transmissions from those who are undiagnosed is now likely to be higher, as most people begin treatment promptly and reach an undetectable viral load sooner.

Timely testing reduces late diagnosis, saving long-term costs in treatment and care

While HIV diagnoses have declined, late diagnosis (CD4 cell count <350 cells/mm^3) remains persistently high (43% in 2018).[6]

Late diagnosis is linked to increased rates of illness, hospital admission and mortality, as well as reduced life expectancy.[7] Individuals diagnosed late are ten times more likely to die within a year of diagnosis.[8] An individual diagnosed very late (CD4 <200 cells/mm^3) is thought to have a life expectancy at least ten years shorter than somebody who starts treatment at CD4 350 cells/mm^3.[9]

There are also clear economic benefits to timely HIV testing. Each HIV diagnosis costs the NHS between £280,000 and £360,000 in lifetime treatment.[10] Costs of care in the first year after diagnosis double if the patient is diagnosed late, because of the significant rates of associated morbidity. Thereafter, the costs of HIV care remain 50% higher for each year following diagnosis.[11]

Reduced rates of late diagnosis (and therefore chronic morbidity) will also reduce the need for and cost of Local Authority-provided social care. Research suggests that social care and support accounts for around 30% of the annual cost of providing HIV treatment and care in the UK.[12] Additionally, analysis of reasons for people with HIV requesting emergency financial help found that the third most common reason was poor physical and/or mental health, usually linked to late HIV diagnosis.[13]

Testing can reduce health inequalities

The Public Health Outcomes Framework, against which the public health performance of Local Authorities is assessed, has as one of its two high-level outcome measures: 'Reduced differences in life expectancy and healthy life expectancy between communities (through greater improvements in more disadvantaged communities)'.[14]

HIV disproportionately affects marginalised and socially excluded people. In 2019, Public Health England (PHE) reported that MSM remain the group most affected by HIV, with an estimated 8.8% of MSM in England living with HIV. Amongst heterosexuals, Black African adults are the largest group affected, with an estimated 3.7% living with HIV.

There are also inequalities within these populations. For example, late diagnosis amongst Black African men in 2018 was at 66%, compared with the overall average of 43%.[15]

There are also significant inequalities between different parts of England. In 2018, 95% of people living with HIV in London had been diagnosed, whereas this drops to 92% in Manchester. Similarly, late diagnosis rates in London were 37%, but were 51% in Yorkshire and Humber.[16]

5 Phillips AN et al., 2013, 'Increased HIV Incidence in Men Who Have Sex with Men Despite High Levels of ART-Induced Viral Suppression: Analysis of an Extensively Documented Epidemic.' *PLoS ONE* 8(2): e55312
6 PHE, 2019, *HIV in the United Kingdom… 2019 report*, *op. cit.*
7 May M et al., 2011, 'Impact of late diagnosis and treatment of life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK CHIC) Study', *BMJ* 343. d6016
8 Brown AE et al., 2012, 'Auditing National HIV Guidelines and Policies: The United Kingdom CD4 Surveillance Scheme' *Open AIDS Journa*l, 6:149–55
9 Anderson J, 2014, 'Leaving it late: why are people still dying from HIV in the UK?' *Public Health Matters blog*. [https://publichealthmatters.blog.gov.uk/2014/12/01/leaving-it-late-why-are-people-still-dying-from-hiv-in-the-uk/]
10 Nakagawa F et al., 2015, 'Projected Lifetime Healthcare Costs Associated with HIV Infection.' *PLoS One* 10(4): e0125018
11 NICE, 2016, *HIV testing: increasing uptake among people who may have undiagnosed HIV. Economic assessment: resource impact of recommendations* [https://www.nice.org.uk/guidance/ng60/documents/economic-report]
12 Mandilia S et al., 2010, 'Rising population cost of treating people living with HIV in the UK', 1997-2013. *PLoS One*, 5(12): e15677.
13 NAT & Terrence Higgins Trust, 2010, *Poverty and HIV 2006-2009* [https://www.nat.org.uk/sites/default/files/publications/Sep-2010-Poverty-and-HIV-2006-2009.pdf]
14 The Public Health Outcomes Framework [https://fingertips.phe.org.uk/profile/public-health-outcomes-framework]
15 PHE, 2019, *HIV in the United Kingdom… 2019 report, op. cit*.
16 PHE, 2019, PHE Centre and London Sector HIV data tables to end December 2018. *Tables No. 2: 2019* [https://www.gov.uk/government/statistics/hiv-annual-data-tables]

Providing testing appropriately and according to the level of need will therefore help commissioners in public health to deliver reductions in health inequalities

1.4 The role of community testing

1.4.1 Current policy

National HIV testing guidelines recommend the provision of testing in both clinical and community settings. [17] NICE (National Institute for Health and Care Excellence) recommends that community testing is offered in:

- "areas with a high prevalence or extremely high prevalence of HIV, using venues such as pharmacies or voluntary sector premises (for example, those of faith groups)
- venues where there may be high-risk sexual behaviour, for example public sex environments, or where people at high risk may gather, such as nightclubs, saunas and festivals."

Diagnosed HIV prevalence bands

Low: HIV prevalence less than 2 per 1,000 residents aged 15 to 59 years.

High: HIV prevalence between 2 and 5 per 1,000 residents aged 15 to 59 years.

Extremely high: HIV prevalence of 5 or more per 1,000 residents aged 15 to 59 years.

Areas with high or extremely high prevalence of HIV are not the only places where community testing might be important. Areas with a low prevalence of HIV may have high rates of late diagnosis or contain populations that are at increased risk of HIV and who may not be accessing SHS. PHE recommends that all local authorities should: "consider how they can ensure that their population groups at increased risk can access HIV testing online and in community settings."[18]

The case for community testing is also supported by international guidance. The European Centre for Disease Control (ECDC) asserts that "community-based testing ought to be an integral part of national testing strategies" and is effective in reaching populations most affected by HIV, vulnerable, or not in touch with traditional healthcare services.[19]

The World Health Organisation (WHO) also recommends the expansion of community-based HIV testing to increase access to testing amongst key populations.[20]

1.4.2 Why test in the community?

It can be more accessible and acceptable

A recent systematic review of HIV testing in Europe concluded that community-based testing is an acceptable and effective strategy for reaching populations at higher risk of HIV that may not be accessing testing in traditional healthcare settings.[21]

In England SHS are provided on an open-access basis, meaning that anyone is entitled to access them anywhere in the country. Yet in spite of this we know that many people do not. This can be for a number of reasons, including:[22]

- Stigma around sexual health and concerns about being seen
- Inability to attend services due to opening hours or location
- Limited knowledge of the health system, including where and how to get tested
- Lack of perceived personal risk resulting in the belief that testing is unnecessary

17 NICE, 2016, HIV testing:increasing uptake among people who may have undiagnosed HIV (guideline NG60). [https://www.nice.org.uk/guidance/ng60]
18 PHE, 2018, *Progress towards ending the HIV epidemic in the United Kingdom: 2018 report* [https://www.gov.uk/government/publications/hiv-in-the-united-kingdom]
19 ECDC, 2018, *Public health guidance on HIV, hepatitis B and C testing in the EU/EEA - An integrated approach* [https://www.ecdc.europa.eu/en/publications-data/public-health-guidance-hiv-hepatitis-b-and-c-testing-eueea]
20 WHO, 2015, Consolidated guidelines on HIV testing services: 5Cs: consent, confidentiality, counselling, correct results and connection [https://apps.who.int/iris/handle/10665/179870]
21 Croxford S et al., 2019, *Community-based HIV testing in Europe: a systematic review* (Poster), HepHIV 2019 Conference, 28-30 January 2019, Bucharest, Romania [https://www.eurotest.org/Portals/0/PS4_04.pdf]
22 These reasons are informed by interviews conducted with the individuals and organisations listed in Acknowledgements, as well as by range of literature. This includes: ECDC, 2018, *Public health guidance on HIV, op. cit*.; NICE, 2011, *Barriers to HIV testing – Final full report* [https://www.nice.org.uk/guidance/ng60/evidence]; Deblonde J et al., 2010, 'Barriers to HIV testing in Europe: a systematic review' *Eur J of Public Health 20*: 422–432.

- Sexual health is not always a priority, particularly for people with complicated lives
- Concerns about migration status, financial costs, and the sharing of personal information
- Previous negative experiences with healthcare, such as that relating to gender identity
- Difficulty getting appointments due to demand outstripping supply
- Fear of the possibility of a diagnosis, or fear of the test itself.

Community testing overcomes many of these barriers and is able to reach those who do not engage with SHS.[23] This is because:

- Community testing enables people to test in spaces they are comfortable in at times that are convenient to them.
- The involvement of target populations in the design and delivery of services ensures that services are adapted to their specific needs, and are accessible and acceptable to them.
- Concerns, such as those around immigration status, can be addressed in an environment in which people feel safe and in language that people can understand.
- Testing in community settings typically (though not exclusively) uses rapid testing technologies. Such tests are quick, non-invasive, and provide results on the same day.
- Outreach work allows CTPs to raise awareness of HIV – and encourage people to test – outside of clinical spaces. These conversations are often necessary to address fears and misconceptions, and empower people to make the decision to get tested.
- Taking testing out of formal healthcare settings can reduce stigma and normalise testing, encouraging people to see it as a routine component of looking after one's wellbeing.
- The HIV test can be delivered as a routine part of a wider health intervention such as blood-borne viruses (BBV) screening which may enhance acceptability to some and increase normalisation.

This culturally competent approach, and the act of 'taking testing to where the community is,' is identified by many CTPs as fundamental to their success in engaging people who are less likely to access traditional health services.

It is part of a strategic, whole systems approach to testing

To reach all populations, it is recommended that testing be available in a range of both medical and non-medical settings.[24] Commissioners of sexual health must therefore consider the role of all parts of the system as part of a strategic approach to testing. This will ensure that different services work together effectively to make testing options available that meet a broad spectrum of needs.

Ongoing cuts to public health spending have resulted in intense pressure on SHS, with spending on sexual health cut by 18% in real terms between 2014/15 and 2018/19.[25] In this climate non-statutory services such as community testing are often sidelined, yet community testing supports statutory services by providing an additional pathway into treatment and care for people living with HIV.

While funding for sexual health has declined, demand has increased, with a 15% rise in attendances over the past five years.[26] CTPs deal predominantly with asymptomatic patients, allowing SHS to focus on symptomatic patients and those with complex medical needs. CTPs can also facilitate 'channel-shift': supporting clients to begin using online services, such as the national self-sampling service, thus further reducing pressure on sexual health clinics.

It mobilises existing community resources

CTPs are community-based and tend to offer HIV testing alongside a range of other services. As a result, CTPs develop strong links to their local communities. Key features that facilitate this include community-based staff and volunteers,

23 HIV-COBATEST, 2017, *A guide to do it better in our CBVCT centres: Core practices in some European CBVCT centres* [https://cobatest.org/conferences-and-publications/]
24 ECDC, 2010, *HIV testing: increasing uptake and effectiveness in the European Union* [https://www.ecdc.europa.eu/en/publications-data/public-health-guidance-hiv-testing-increasing-uptake-and-effectiveness-european]
25 Finch D, 'Health investment needs long-term thinking,' *The Health Foundation blog*. [https://www.health.org.uk/blog/health-investment-needs-long-term-thinking]
26 PHE, 2018, *Sexually transmitted infections and screening for chlamydia in England, 2018* [https://www.gov.uk/government/statistics/sexually-transmitted-infections-stis-annual-data-tables]

peer-led services, partnerships with other local services, and community development and outreach.[27] This approach can engender trust and facilitate greater access to groups that are often socially marginalised. This trust, and the use of community-based staff and volunteers, can in turn help to challenge HIV-related stigma within the local community.

By drawing on and mobilising existing community assets, community testing is therefore able to maximise engagement. This is particularly important in areas where sexual health provision is sparse or where test coverage of key populations is known to be low.

It can be targeted, flexible and innovative

Additionally, community testing enables commissioners to more effectively target resources and provision for vulnerable communities. In 2018, of those testing in SHS, 11% were MSM, 4% were heterosexual Black Africans, and 4% were born in high prevalence countries. In other words, these key populations accounted for less than 20% of all tests in SHS.[28] In comparison, 51% of those testing in community settings were MSM, 13% were Black African, and 3% were born in a high prevalence country.[29]

CTPs are often able to be more flexible than traditional healthcare providers, enabling innovative approaches to service delivery tailored to specific populations. Effective community testing is nimble and able to adapt quickly to demand; this ability to respond quickly to emerging need is demonstrative of how community testing can support the wider system.

Although CTPs see far fewer clients than SHS, testers may have more time per client, which enables a broader and more in-depth intervention to be delivered.

It enables effective health promotion

Diagnosing HIV is of course the fundamental objective of conducting an HIV test. However, the test also facilitates a wider health promotion intervention.

Health promotion is defined by the WHO as: “the process of enabling people to increase control over, and to improve, their health.”[30] Sexual health is a core component of overall health and wellbeing, yet for many people it remains a taboo. Community testing provides an opportunity to initiate conversations about sexual health and wellbeing relevant to the individual’s needs, thereby increasing knowledge and normalising discussions about sex and HIV. It promotes self-care and empowers people to manage their own sexual health; this is central to a prevention-led approach to healthcare.

Community testing also provides a gateway to other services and a means of assessing wider health needs. Sexual health, and health in general, is affected by a wide range of social and structural factors. CTPs use the HIV test to identify factors that increase risk and vulnerability and to assess wider health needs, such as those related to drug and alcohol use.[31] CTPs are then able to address these issues, either directly (for example by offering an STI screen or referring clients to other services internally) or by providing linkage to relevant external services.

It is part of a Combination HIV Prevention approach

Combination HIV prevention seeks to have the maximum impact in reducing HIV incidence through the implementation of complementary behavioural, biomedical and structural interventions.[32] This approach is recognised as one of the principal reasons for recent declines in HIV diagnoses in the UK.[33] Current key components include condom provision, pre-exposure prophylaxis (PrEP), prompt initiation of ART on diagnosis (treatment as prevention), and expanded HIV testing.

27 These features will be explored in later sections.
28 PHE, 2019, *HIV in the United Kingdom: Towards Zero HIV transmissions by 2030, 2019 appendix* [https://www.gov.uk/government/publications/hiv-in-the-united-kingdom]
29 Data received in a data request from Public Health England, January 2020.
30 WHO, 1986, *Ottawa Charter of Health Promotion* [https://www.who.int/healthpromotion/conferences/previous/ottawa/en/]
31 See https://www.makingeverycontactcount.co.uk/ for information and resources to support this approach.
32 UNAIDS, 2010, *Combination HIV Prevention: Tailoring and Coordinating Biomedical, Behavioural and Structural Strategies to Reduce New HIV Infections - A UNAIDS Discussion Paper* [https://www.unaids.org/en/resources/documents/2010/20101006_JC2007_Combination_Prevention_paper]
33 PHE, 2018, *Progress towards ending the HIV epidemic in the United Kingdom: 2018 report* [https://www.gov.uk/government/publications/hiv-in-the-united-kingdom]

UNAIDS define combination prevention programmes as rights-based, evidence-informed, and community-owned. Such programmes are:

- Tailored to national and local needs and contexts
- Focused on immediate risks as well as underlying causes of vulnerability
- Based on community-centred approaches to address social determinants of health
- Flexible and adaptive to changing patterns and can rapidly deploy innovation.

Community testing exemplifies these features, as is demonstrated above. It also complements other key components of HIV prevention by supporting earlier diagnosis, encouraging condom use (and often providing condoms), supporting risk reduction, raising awareness of post-exposure prophylaxis (PEP) and PrEP, facilitating regular testing, and providing onward referrals.

1.5 Community testing in England: what we know

Community-based HIV testing has been conducted in England for well over a decade. The nature of community testing means that it is less likely to be linked to national systems and institutions that routinely monitor and report. Whereas SHS report directly to PHE through GUMCAD (England's STI surveillance system), providers of community testing have traditionally reported only to their relevant commissioners. This is not standardised and has not normally fed into national data.

Since 2016 however, PHE has begun to collect and publish data on community testing as part of its annual reporting on HIV.

In 2018, 46,258 HIV tests were reported to have taken place in community settings, an increase of almost 50% upon the previous year.[34]
It is important to note that data is collected through a voluntary survey, so the number of tests reported each year is an underestimate. **We recommend that all CTPs submit testing data to PHE's annual community testing survey.**

According to the 2018 survey, overall test reactivity in community settings was 0.4%.[35] In SHS, the overall positivity rate was 0.1%. While these rates cannot be directly compared (a minority of reactive results will be false positives[36]), they nonetheless clearly demonstrate the ability of community testing to reach those at higher risk of infection.

Further to this, 30% of clients (where testing history was known) in community settings had never tested previously for HIV.[37] This shows that community testing can be effective in reaching people who are not testing in traditional healthcare settings.

34 PHE, 2019, *HIV in the United Kingdom… 2019 report, op. cit*.
35 *Ibid*.
36 A reactive result indicates the presence of HIV, but the result is only preliminary and must be followed by a confirmatory blood test. A false positive is a test result that says a person has HIV when they do not. See section D.1 for more information.
37 Data received as part of a data request from Public Health England, January 2020.

2. Developing community testing programmes

2.1 Principles of community testing

There are key principles that should underpin provision of community testing. How to ensure that these principles are met will be explored throughout this toolkit.

To be effective, community testing must be:

1) **Voluntary –** HIV testing is voluntary and clients should never feel coerced to test. Individuals must be provided with knowledge that enables and encourages them to make an informed decision to test.
2) **Confidential –** clients must be assured that the service is strictly confidential and that any personal details provided will not be shared without their explicit consent. This is vital to establish trust.
3) **Accurate –** tests must be CE-marked and chosen in accordance with national guidelines. Clinical governance providers should be consulted to ensure that tests are fit for purpose, and processes must be in place to ensure that clients receive correct results.
4) **High quality –** services must be clean, safe, and delivered by trained staff or volunteers in accordance with health and safety and clinical governance arrangements. This is important to counter the false perception that testing outside of traditional healthcare settings is inferior.
5) **Linked to relevant services –** all clients who receive a reactive result should be swiftly referred to SHS for confirmatory testing, and all who need it should have prompt linkage to treatment, care and other services relevant to their needs.
6) **Client-centred –** services must be tailored to the specific needs of individuals. This means responding to the unique situation and concerns of each client and adapting delivery accordingly.
7) **Accessible –** services should be provided in locations and at times that are convenient to the target population. This may require testing in a variety of different settings and at times outside conventional working hours.
8) **Culturally competent –** understanding of the community is essential, and services should be sensitive to race, gender, sexuality, religion, language, and other cultural factors. This is best achieved by involving target populations in the design and delivery of services.
9) **Non-judgemental –** for many people discussions of sex and sexual health can cause embarrassment or shame. To help people to feel safe and comfortable, services must be inclusive and non-judgemental.

2.2 Objectives

The primary objective of community testing interventions is clear:

To increase testing and diagnosis in order to reduce levels of undiagnosed and late diagnosed HIV.

However, it is important to recognise that this is not its sole function. Even when testing is delivered as an isolated service, it performs a wider role in HIV prevention and health promotion. This can include:

- Normalising HIV testing amongst key populations
- Reducing stigma by increasing knowledge and awareness of HIV
- Empowering people to manage their own sexual health and wellbeing
- Providing a gateway into treatment, care, and other services relevant to their needs
- Linking people into the wider health system.

Connecting people with the NHS

Many people who use community testing services are not registered with a GP. This is particularly common amongst migrants who may have concerns around eligibility, costs of care and requirements to provide documentation regarding their immigration status. It is important that everyone living in the UK is aware of their rights with regards to healthcare:

Everyone is entitled to register with a GP free of charge[38], and there is no legal obligation to provide an ID or proof of address. We strongly recommend that all people are encouraged and supported to register with a GP. This is both to safeguard people's health and to save the NHS money by preventing avoidable visits to A&E.

SHS and Accident and Emergency (A&E) departments are also free of charge for everyone, and should not ask people about their residency status. If people are asked for this information they are entitled not to provide it.

HIV treatment and care is free to anyone in the UK regardless of immigration status, but much of secondary care (care that requires referral to a specialist) is not. This means that some people are eligible to be charged. If clients or CTPs are concerned about this, advice should be sought from Doctors of the World - https://www.doctorsoftheworld.org.uk/contact-us/

2.3 Intervention design

Once CTPs have identified their primary and secondary objectives, they can consider how to design an intervention that can best meet these objectives. The next section aims to support CTPs in determining their strategy for this and looks at:

A. Who to test

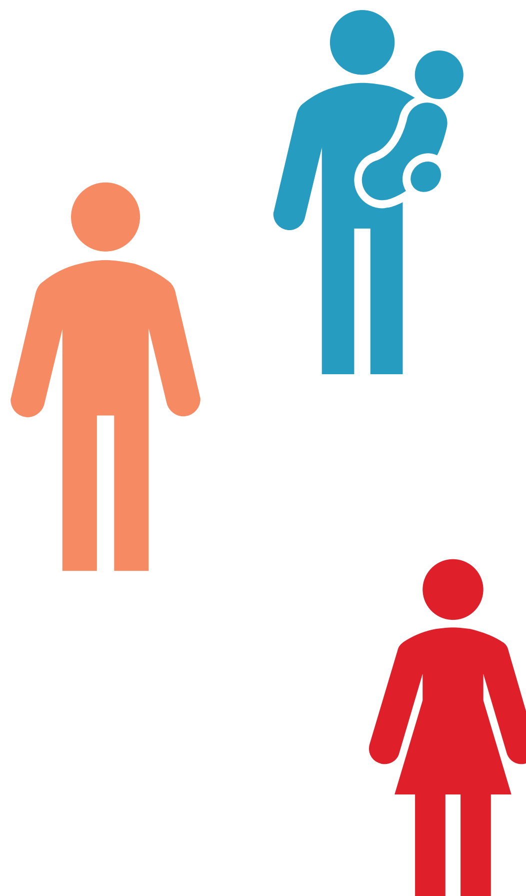
B. How to engage people

C. Staff, training and clinical governance

D. The test itself

E. Before and after the test

Monitoring and evaluation are also central to effective community testing. Guidance on this is provided in NAT's *Community HIV testing: Evaluation Toolkit.*



38 See the government's 'NHS entitlements: migrant health guide.' [https://www.gov.uk/guidance/nhs-entitlements-migrant-health-guide]

A. Who to test

The provision of HIV testing should be based on local prevalence and on how different groups and communities are affected.[39] Community testing services aim to reach people at increased risk of HIV who may not be accessing testing in traditional health services. These are the people most likely to be undiagnosed and who may benefit most from access to testing. Identifying them and targeting services accordingly is therefore crucial.

A.1 Identifying need

In England the communities most affected by HIV are MSM, people of Black African ethnicity, and people born in high prevalence countries. There is also elevated prevalence amongst Black Caribbean communities, people who inject drugs, prisoners, and the sexual partners of these key populations.[40]

Other populations where data is not as conclusive but who we are fairly sure are also at risk include trans[41] people and Latin American people.[42]

Continued monitoring and ongoing improvements to HIV surveillance will help to provide further insight on the impact of HIV on these and other populations.[43]

It is important to note that each of these populations contain numerous subcategories, for which risk and need may vary. Additionally, individuals do not always fit neatly within a single category and those with intersectional identities, such as BAME (Black, Asian and other minority ethnic) MSM, can experience multiple layers of stigma and disadvantage, and increased risk of HIV.

An awareness of key groups is important, especially when coordinating HIV prevention at the national level. However, national trends are not reflective of all parts of the country, and commissioners and CTPs must have a strong understanding of local need.

Accessing local HIV data

HIV data and information for specific regions and local authorities is collected by Public Health England, a key source of evidence and expertise. This includes the following resources:

- **Regional Reports** – annual epidemiological data for each of PHE's nine regions, covering diagnoses, people living with HIV, implications for prevention, and risk groups.
- **Sexual and Reproductive Health Profiles** – data is available for each local authority on HIV testing coverage, repeat testing, new diagnoses, late diagnoses, diagnosed HIV prevalence, prompt ART treatment initiation, and virological success.
- **Local Authority Sexual Health, Reproductive Health and HIV Epidemiology Reports (LASERs)** – annual reports describing HIV and STIs in the local area, including analyses and breakdowns by small geographical area (MSOA) and key STI prevention groups. These aim to inform Joint Strategic Needs Assessments (JSNAs) and enable targeted service provision. Access is restricted to named health professionals, including commissioners.
- **HIV Lens** – An interactive online mapping tool that draws on data from PHE to visualise the impact of HIV on communities across England. HIV Lens is presented by NAM, PHE and Watipa.

39 NICE, 2016, *HIV testing: increasing uptake* (guideline NG60), *op. cit.*
40 PHE, 2019, *HIV in the United Kingdom… 2019 report, op. cit.*
41 Trans is an umbrella term that refers to all people whose gender identity is different from that assigned to them at birth. This includes trans men, trans women, non-binary, and other gender identities.
42 NAT, 2017, *Trans* people and HIV: How can policy work improve HIV prevention, treatment and care for trans* people in the UK?;* Rawson S et al., 2019*, Latin Americans in the UK: a key population for HIV prevention* (Poster), 25th Annual Conference of the BHIVA, 2-5 April 2019, Bournemouth [https://www.bhiva.org/file/5ca73250e4238/P096.pdf]
43 A new code to identify trans attendees in SHS is in the process of being implemented. This will allow for more accurate identification and reporting of trans people attending SHS.

Epidemiological data from PHE should form the basis of any understanding of local need, but there are important considerations for commissioners and CTPs to be aware of:

- England's STI surveillance system (GUMCAD) reports data from SHS, but only around 5% of the adult population in Britain attend SHS each year.[44] Identifying need outside of the clinical population is therefore difficult but important in finding the undiagnosed.
- Population categories are not homogenous groups. Within each category are numerous subcategories, and the knowledge, behaviour and lifestyles of individuals within them are highly varied. Local need may therefore be highly nuanced.
- Services need to be responsive to changes and emerging trends within their populations.[45] CTPs do not always have access to localised epidemiology data, and where they do the data may only be collated annually and therefore unable to immediately identify emerging need.

In light of this, CTPs can themselves be valuable sources of information in identifying populations at risk that might benefit most from community testing. CTPs are demonstrably effective at reaching people who are not accessing SHS, and are therefore well placed to identify need amongst this group.[46] The population data that CTPs collect is also often more stratified than that collected by SHS, and thus can help to indicate which subsets of the population are at particular risk. This can deepen understanding of local need and support effective commissioning. Commissioners are not always able to share trends seen in SHS with CTPs (due to data protection concerns), but where they are this can be useful in enabling them to quickly respond to emerging need.

CTPs can also help to identify behaviours and other factors related to increased risk in the community, as well as who is engaging in these behaviours or affected by these factors. This can help to further segment the target population, thereby increasing the effectiveness of targeting and informing recruitment strategies.[47]

A.2 Targets and eligibility

To restrict or not to restrict?

Often CTPs are commissioned to test specific populations. However, while the majority of CTPs target those groups, many do not restrict testing to individuals in these groups. This is because people testing in community settings often don't test in traditional settings and may be at high risk of HIV, so turning them away can be a missed opportunity and potentially stigmatising. This does however pose a challenge in terms of resources. As a result, how restricted testing is can vary. Options include:

- Restricting testing solely to the target population
- Conducting a preliminary risk assessment to assess whether an intervention is required
- Proportionate universalism: services are universally available but delivered at a scale and intensity proportionate to the degree of need. This is facilitated by the use of effective recruitment strategies discussed in the following section.

Which policy is most appropriate will depend on the capacity and objectives of each CTP.

Commissioners may also restrict funding to testing residents of the local authority. However, we know that some clients seek to access services outside the local authority that they reside in. This may be because they live, work and socialise in different areas, or because they are reluctant to test in their own locality for fear of being recognised and stigmatised. As such, commissioners from different Local Authorities should consider commissioning services collaboratively in order to enable CTPs to serve clients from a wider geographical area. Greater Manchester's Passionate about Sexual Health (PaSH) Partnership and Do It London are examples of this.

44 Tanton C et al., 2017, 'Sexual health clinic attendance and non-attendance in Britain: findings from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)' *Sexually Transmitted Infections*, 94(4): 268–276
45 PHE & Department of Health and Social Care, 2018, *Integrated Sexual Health Services: A suggested national service specification* [https://www.gov.uk/government/publications/public-health-services-non-mandatory-contracts-and-guidance-published]
46 See section 1.4.2
47 Centers for Disease Control and Prevention (CDC), 2013, *Planning and Implementing HIV Testing and Linkage Programs in Non-Clinical Settings: A Guide for Program Managers* [https://www.cdc.gov/hiv/testing/nonclinical/index.html]

Setting targets

Targets for key performance indicators (e.g. number of MSM tested for HIV) are often agreed within contracts between commissioners and CTPs. How targets are set and what they assess varies from contract to contract.

Any targets should be based on local data and set as the result of a dialogue between commissioners and CTPs. Targets that are imposed unilaterally risk being unrealistic and not reflecting local need or organisational capacity. Targets and data should be reviewed regularly to ensure that they remain appropriate and address changes in need.

A.3 Key considerations for commissioners

- Commissioners should ensure that health and wellbeing boards address HIV testing and diagnosis rates in joint strategic needs assessments (JSNAs), considering geographic and demographic variation in need.
- A local sexual health needs assessment (SHNA) should be conducted to support the JSNA and inform sexual health commissioning.[48]
- LASERs, or at least the relevant data within, should be made available to CTPs as recognised providers of HIV testing. This will support CTPs to target services effectively.
- Whilst JSNAs and SHNAs should inform the service specification, commissioners should acknowledge the need to respond to changes and emerging trends on an ongoing basis.
- Commissioners should recognise and value the role that the community sector can play in identifying local need and informing service delivery and transformation. This is particularly relevant to emerging communities that may be obscured by broader demographic trends.
- CTPs can be an important asset in responding promptly to emerging need, using outreach and existing networks to proactively engage affected communities.
- When commissioning community testing, any targets or indicative numbers of tests should be set according to local need and through dialogue between commissioners and CTPs.
- Commissioners should invite CTPs to report data on all attendees (not just those who contribute to targets) to assess and evaluate local demand.
- Newer services may require a lead-in time to become established in their local area. This should therefore be reflected in any targets that are set.
- Commissioners should consider commissioning services collaboratively to provide greater access to clients who wish to test outside of the local authority that they reside in.

48 British Association of Sexual Health and HIV (BASHH), 2019, *Standards for the management of sexually transmitted infections (STIs)* [https://www.bashh.org/about-bashh/publications/standards-for-the-management-of-stis/]

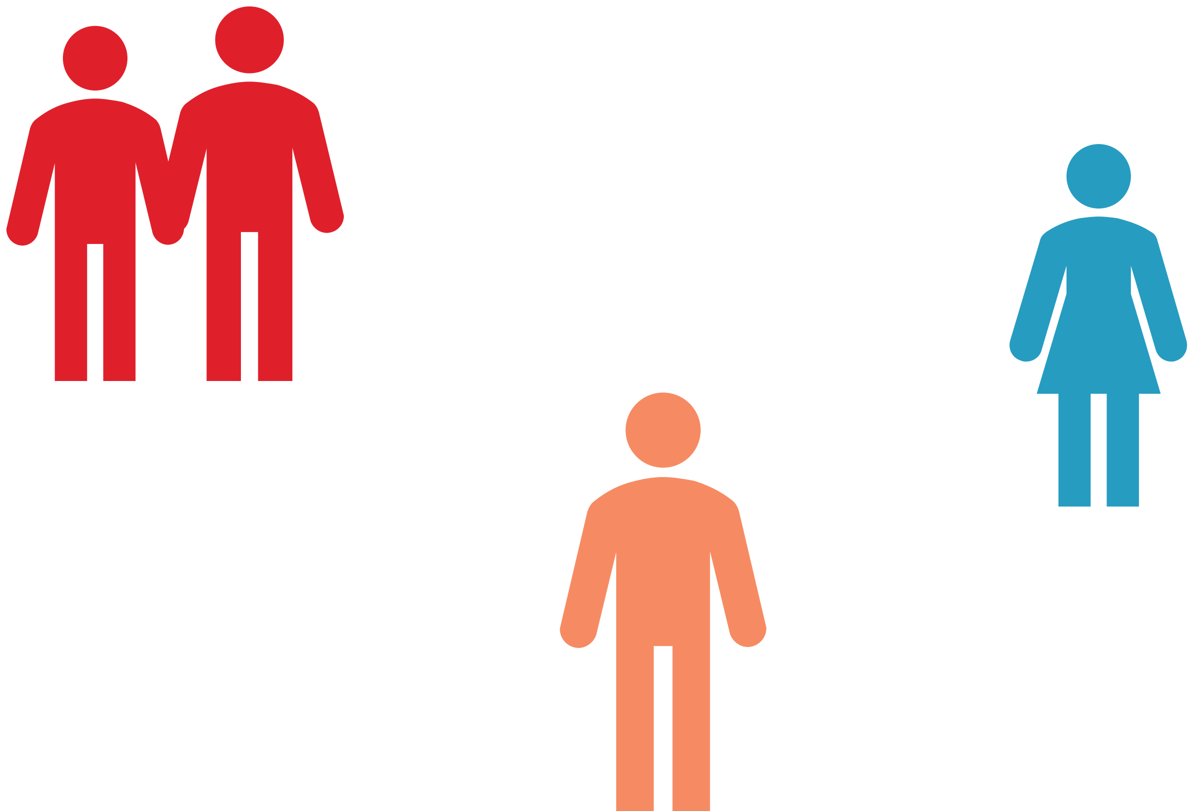
Case study: Community partnerships to increase access to testing for sex workers (LGBT Foundation)

LGBT Foundation offers HIV and STI testing in a range of outreach settings across Greater Manchester. This enables them to reach marginalised communities and people living in isolation. LGBT Foundation has identified sex workers as one such population, and has found that this group are less likely to access traditional healthcare settings.

To reach this population LGBT Foundation have partnered with a local charity, The Men's Room, which supports male and trans sex workers. By providing monthly rapid HIV testing at the Men's Room, LGBT Foundation have been able to reach first time testers, see repeat testers, and deliver reactive results.

The service provides immediate results and there is no requirement to book an appointment. By meeting sex workers at services where they already are, LGBT Foundation have eliminated barriers associated with accessing traditional healthcare settings, as well as barriers associated with accessing LGBT Foundation's own facilities. Male sex workers may have sex with men but not identify as LGBT, or may fear being stigmatised both for their sexuality and their profession.

The testing session is structured as a one-to-one Test & Talk model. This ensures that as well as testing, LGBT Foundation can offer wellbeing support and information around signposting and advocacy relevant to the clients' needs. Once a relationship of trust has been established clients can also be more likely to attend LGBT Foundation's offices for a full STI screen if required.



B. How to engage people

Once a target population is identified, it is necessary to consider where, when and how to engage them in testing. This will of course depend on the specific needs and characteristics of the population in question, but for the purpose of this toolkit we have drawn on international guidance and the experience of current CTPs in order to establish principles and share learning.

B.1 Where and when to test?

One of the core principles of community testing is taking testing to where people are. That is, taking testing out of healthcare settings and into the community.

The specific locations that community testing can take place in are varied, but can be grouped into two main categories: in-house settings and outreach settings.

In-house settings

Most CTPs offer testing on their own premises in a suitable private space. Though these are often described as 'clinics' they are not medical spaces in the traditional sense, and in fact most CTPs actively avoid creating a medicalised environment. In-house settings tend to provide a regular service via drop-ins, appointments or a combination of both. These services are often open access but can also be restricted to a certain community, either for reasons of targeting or accessibility. For example, some CTPs offer regular sessions specifically for sex workers due to heightened concerns about confidentiality amongst this group.

Outreach settings

Other settings where testing is offered include community centres, faith venues, educational institutions, libraries, bars/clubs, sex-on-premises venues, public sex environments, gyms, saunas, hostels, refugee and asylum services, sex shops, barbers/hairdressers, market stalls, community organisations, mobile units (e.g. buses – see METRO case study), and events (Pride, festivals, fairs, sports tournaments, etc).

Testing in outreach settings may be offered on a regular basis at designated times, either via drop-in or appointment, or on a more ad-hoc basis - often described as 'pop-up' testing.

Developing positive relationships with stakeholders that provide access to outreach settings is crucial. Stakeholders may be reluctant to enable testing as a result of stigma, incorrectly held beliefs about HIV, or business concerns. Others may be reluctant to acknowledge the sexual behaviour of service users. CTPs should be prepared to address any concerns and persuade stakeholders of the benefits of testing to the community. They should also be prepared to adapt their approach if necessary, for example, by considering the use of a different type of test or offering testing as part of a wider health check-up. If testing on-site is not initially feasible, the possibility of conducting outreach (see section B.2) should be explored, both as a means of fostering trust and reaching people in need.

Ensuring that services are accessible

To be effective in engaging target groups, community testing must be accessible and convenient to them. Identifying appropriate settings and opening times is central to this. To do so, CTPs should consider the following questions:

- **Where will the target population be found?**

Identify suitable locations. This will involve consideration of where the target population lives, works, and socialises. Staff/volunteers may be members of the community themselves, and service users and the wider community – and organisations working within it – should also be consulted.

- **Where will the target population feel comfortable?**

Some people may be unable to attend in-house clinics, either for logistical reasons or because of concerns around visibility and stigma. To ensure that as many people feel able to test as possible, testing should be offered in both in-house and outreach settings, and in spaces that are neutral and discreet.

- **When should testing be offered?**

Opening times should include out of normal office hours and weekends. If people are unable to access the service they should be directed to alternative community, online or clinical services.

Accessibility checklist

Not all settings are appropriate for providing community testing. CTPs should ensure that:

- ☐ Wherever possible, services are physically accessible, with disability access and proximity to parking and/or public transport.
- ☐ Services consider the communication needs of patients, and where possible are accessible to non-English speakers, the visually impaired, and the hearing impaired.
- ☐ Spaces are safe, welcoming, and non-judgemental. Materials and resources available and on display should be inclusive and relevant to the communities in question.
- ☐ The environment is clean, tidy and well-managed, in accordance with the clinical governance in place (see section C.2).
- ☐ The test itself is conducted in a secluded or private area that guarantees confidentiality.
- ☐ The performance of different settings is regularly reviewed. Feedback from patients is sought and acted upon, and if necessary alternative locations are considered.

Case study: Going to communities with mobile testing (METRO)

In addition to testing in fixed venues, METRO offers mobile testing using a specially modified bus. This can be parked in areas of high footfall where specific target groups are known to be found. Outreach workers conduct street-based outreach in the vicinity to recruit people to test. This allows METRO to engage people who are less likely to access clinical services, including people with drug and alcohol issues, homeless people, and people with insecure immigration status.

The bus offers people a fast, convenient service with immediate results and no requirement to book an appointment. The entire process usually takes less than 30 minutes, enabling people working nearby to test on their lunch break. In the bus itself there is a private space for testing and a waiting area which fits around 4 people. Whilst waiting to test, clients complete a registration form and questionnaire which assesses risk behaviours.

METRO have found that this approach is particularly effective when using branding from national campaigns (e.g. Give HIV the Finger) and when outreach workers include community peers. Delivering HIV testing alongside other sexual health services (such as condom schemes or the National Chlamydia Screening Programme) also improves the acceptability of the offer.

The presence of sexual health messaging is effective in starting conversations even if people choose not to test, and some clients who present in-house report that they learnt about the opportunity through the mobile service. Social pressure can be a notable factor in the decision to test, particularly amongst groups of men; if one member of a group can be encouraged to test, often the rest of the group will follow suit. Approaching groups can therefore facilitate the engagement of many first-time testers and reduce stigma within the community. Clients are prepared for the possibility of a reactive result and supported to maintain their confidentiality.

Case study: Delivering testing in a sauna (Terrence Higgins Trust)

Terrence Higgins Trust (THT) offers rapid HIV testing (see section D.1) and STI screening at Brighton's most popular gay sauna, The Brighton Sauna. The service takes place on Wednesday evenings from 6pm-8.30pm and requires no appointment. It is free and anonymous, and open to sauna users as well as other MSM who can choose to test without using the sauna. A significant proportion of the men tested say they do not access local SHS, so for many the service is a unique opportunity to test and receive sexual health advice.

THT provide men with information and support before and after the test, and anyone who receives a reactive result is immediately referred to local SHS for confirmatory testing via a pre-established and agreed referral pathway. The service has tested hundreds of men and has identified many previously undiagnosed HIV infections. STI screening for chlamydia, gonorrhea and syphilis is offered alongside the HIV test, and the majority of clients elect to be tested for all.

Prior to launching the testing service THT established a good working relationship with the venue through physical outreach sessions and free condom, lubricant and static resource distribution. THT worked with the sauna owners to gain permission to test on the premises, and conducted a survey, focus group and qualitative interviews with sauna users to seek views and feedback on how people felt about testing in the venue. The survey of over 400 local MSM who use saunas suggested high approval, with over 70% of respondents supporting the scheme.

The suitability of the venue was assessed to ensure it offered a physical space to offer testing which reached the required hygiene and infection control standards and also provided a confidential space. THT ensures standards are maintained by making necessary adjustments to the environment, such as selecting spaces that ensure client consultations will not be overheard.

THT has developed a robust Confidentiality Policy based on guidelines issued by the General Medical Council and the Department of Health's 'Confidentiality – NHS Code of Practice' paper. This policy is applicable to all staff and volunteers. Laptops taken to the sauna are connected to a secure network and patient data is managed through a CRM system and in accordance with THT's Information Security Policy. Laptops are secured with encryption codes and measures are put in place to ensure laptop screens are not visible or left unattended.

B.2 Recruiting clients

Community-sector organisations are community led and often have a history of working within the communities they serve. Sexual health and HIV are topics that remain stigmatised, so engaging people from a position of trust is important.

Organisations should develop clear messaging and resources to facilitate recruitment. This is an opportunity for wider HIV prevention work, which may indeed be a primary aim of the project. Information about HIV and prevention must be up to date and tailored to the relevant population. CTPs should therefore consider providing condoms and information about PEP, PrEP, other STIs and local sexual health services.

To recruit effectively, CTPs should use a combination of the methods discussed below, adapted to the populations in question. Each method has its own strengths and limitations so the key to an effective strategy is using them together to maximise reach.

Methods of recruitment

Physical outreach

Physical outreach can consist of **street-based**, **venue-based**, and **event-based outreach** and involves identifying and engaging members of the target population out in the community.

Settings commonly include bars and clubs, saunas, faith venues, markets, shops, universities, colleges, public sex environments, public spaces, and events. Developing relationships with individuals who provide access to these spaces is essential, and details of the service should be clearly communicated to them.

Sometimes outreach can be conducted alongside testing itself, in which case people can test immediately. Often it is used to encourage people to test at a later time. Conducting conversations out in the community can normalise sexual health and HIV testing, thereby destigmatising HIV and influencing community norms. Sometimes simply being visible allows people to know that support is available; people may not feel comfortable engaging in public but will know who to contact in future.

CTPs should consider how to reach those who might not access identified spaces. For example, gay bars may be an effective way to reach many gay and bisexual men, but not all MSM will attend these spaces. CTPs should therefore consult members of the population to identify a range of spaces to enable the widest possible engagement.

Staff/volunteer safety is paramount in all outreach settings, and risk assessments should be conducted before outreach takes place.

Online outreach

This is different to online marketing, detailed below, as it involves actively engaging with people via chatrooms, forums, and dating or hook-up sites. These are often app-based. As many online spaces are demographic-specific, for example hook-up app Grindr, this can be a highly effective way of reaching target groups.

CTPs may be able to create user profiles through which they can communicate directly with members of the community. One example is the use of escort sites for male sex workers. This group might not be reached through traditional gay and bisexual spaces and may not access mainstream services due to fear of stigma. Online outreach allows CTPs to develop a relationship of trust before individuals come to test, and ensures that any questions or concerns can first be addressed in a safe online space.

Community organisations often have a member of staff for whom online engagement is a specific responsibility, and are therefore highly adept at using this approach. Not all online platforms are free to access, and some have regulations about using them for promotional purposes. Specialist knowledge and sensitivity are therefore required to navigate and utilise these platforms successfully and ethically.

Marketing

This includes use of leaflets and flyers, posters, print media, radio and television, social media, and the internet to encourage testing. An effective and culturally competent communications strategy will involve a combination of these methods adapted to the relevant community, with consideration given to linguistic needs. New opportunities should continually be sought, with recent examples including live-streaming of testing on social media, and the use of influencers.

In addition to developing their own marketing materials, CTPs can utilise existing resources. HIV Prevention England produce a suite of HIV testing and prevention resources, while campaigns such as National HIV Testing Week provide an opportunity to reach wide audiences while HIV is on the national agenda.[49] CTPs should consider the language used in marketing materials and ensure that it is inclusive and non-stigmatising.[50]

It is also important to consider representation. Representing the target population, for example through imagery, may make members of that population more likely to engage with the service. However, making communities feel exclusively targeted can itself be perceived as stigmatising or problematic. How to market the service effectively and inclusively should therefore involve consultation with the populations in question, and be based on what works best for them.

49 [https://www.hivpreventionengland.org.uk/]

50 Namiba A et al., 2019, 'NHIVNA Best Practice. The language of HIV: a guide for nurses' *HIV Nursing*, 19(2): BP1–BP4 [https://www.nhivna.org/file/5dcbdcb83254e/BP-19-2.pdf]

Case study: Engaging people in testing and support through Hook-up apps (Spectra)

Spectra in London uses hook-up apps as one means of engaging prospective clients, especially when testing in outreach settings. To do so the team creates a user profile advertising the service on offer. The profile is usually called "HIV testing" alongside details of where and when the service is and what it involves. Spectra proactively messages users who are online in the vicinity, informing them that the service is available and inviting them to attend.

> “It is really important to be both friendly and open to the responses you receive. Always avoid being pushy or applying any pressure at all. Simply ask if they are interested, and if the answer is ‘no,’ politely say goodbye. If the answer is ‘yes’ then give any other details they might want. Providing your name, for example, can make accessing a service less intimidating.”

Spectra has found this approach to be effective in recruiting clients. A recent example was a client who engaged with the service through a hook-up app for MSM. The man was accessing PrEP but was very anxious about an experience he’d had at a chemsex[51] party and wanted to be tested. At the party he had been subjected to non-consensual sex, and was experiencing anxiety and trauma. Spectra’s outreach worker explained that it was too soon to be reliably tested for HIV, but that if he came to the office he could be tested for other STIs. With the client’s consent, the outreach worker also referred him to an in-house counsellor.

Consequently, the client was tested for STIs (and eventually HIV) and completed 12 sessions of counselling in which he worked through underlying issues related to addiction. During this time, he stopped using drugs completely, reported better adherence to PrEP, and was able to talk to the police about crimes he’d witnessed and been victim to.

Note: Apps may delete user profiles if they are identified as spam. To avoid this, messages should be varied rather than generic. Many apps only delete profiles if other users report them, so being polite and friendly is the best means to avoid deletion. If profiles are blocked, contacting the App and explaining why you are using their service may result in the profile being unblocked.

Referrals

Most CTPs deliver HIV testing as part of a range of services. This may include services relating to sexual health - such as counselling, workshops and HIV support - or other services relevant to the target population, such as substance abuse and mental health programmes. These services provide an opportunity to identify relevant individuals and signpost them to get tested.

People may also be referred externally. This requires building relationships with organisations that work with the target community and training them on how to promote testing effectively. A sexual health component could be incorporated into the organisation’s existing services, for example the marriage counselling offered by some African-majority churches. Another example is drug and alcohol services that do not deliver their own HIV testing.

Community champions

Some CTPs use an asset-based ‘community champions’ model to recruit. This involves developing relationships with community leaders and people of influence who can act as gatekeepers to the wider community. As role models, community champions can influence behavioural norms and are able to speak to their peers in language that they understand and trust. One common example of this is faith leaders who may encourage their congregations to get tested or allow CTPs to come and speak to the congregation with their support.

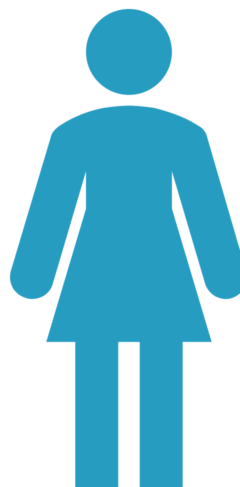
Sensitivity to cultural needs and attitudes is very important, so involving community leaders in the design and delivery of such sessions and inviting them to test first can be fundamental in increasing acceptability. Testing may then be offered on site, which is both convenient and a powerful way to tackle stigma.

51 chemsex refers to the sexualised use of recreational drugs, particularly amongst MSM. It typically involves the use of GHB/GBL, crystal methamphetamine and/or mephedrone.

One limitation that CTPs should be aware of is the potential for community gatekeepers to deny access to the community rather than provide it. This may be due to their own stigma around HIV or a reluctance to allow external organisations to deliver a service in their space. CTPs are highly competent at challenging stigma and should be persistent, demonstrating flexibility and a willingness to adapt their approach to address concerns. Asking an existing community champion to attest to the benefits of the service may also help to overcome resistance.

Recruitment checklist:

- ☐ Develop a holistic recruitment strategy that considers a range of different methods.
- ☐ Adapt recruitment methods to the needs of the target population and its various subsets.
- ☐ Consider the capacity, safety, and expertise of staff/volunteers.
- ☐ Employ and train designated recruitment or outreach workers.
- ☐ Build strong working relationships with organisations and individuals that facilitate outreach.
- ☐ Be creative and innovative, and utilise new and emerging technologies.
- ☐ Share learning with other CTPs who work with similar target populations.



C. Staff, training and clinical governance

To be successful community testing must be both accessible and professional. The target population must feel comfortable and secure, but must also be assured that the standard of the service is equal to that of statutory services. Competent staff/volunteers and robust systems of clinical governance are essential to achieve these outcomes.

C.1 Who should deliver the tests?

For the purpose of this toolkit we will focus on staff/volunteers that are directly involved in the provision of testing.

Community testing is typically delivered by lay testers: non-clinical practitioners. In England this is permitted provided that testers are competent to deliver testing and have access to clinical support and supervision.[52] The WHO supports lay testing on the basis that it can increase the uptake of testing, is sufficiently accurate, can cost less, is supported by patients, and can be more culturally sensitive.[53]

Many lay testers are paid staff. When testing takes place in outreach settings there is an obvious benefit to testers also being trained in conducting outreach. Some CTPs deploy pairs of lay testers in such settings, with one carrying out the tests and the other performing outreach and administration.

CTPs may also use volunteers as lay testers. This can significantly extend the reach of the service. Some CTPs have had concerns about the use of volunteers as lay testers due to the level of investment required in terms of training and support, and issues of commitment and confidentiality. However, with robust application and training processes and the use of clear confidentiality agreements, using volunteer testers may bring significant benefit. These include increased organisational capacity and improved representation of the target community.

Some CTPs additionally offer nurse-led sessions in partnership with local SHS. These sessions typically offer full STI screening and may also include vaccinations.

However, this is less common and some previously nurse-led services have transitioned to the use of lay testers as it decreases staffing costs and new technologies mean that lay testing is possible for most STIs.

Community representation

The involvement of the target community in the planning and delivery of services is a core component of community testing. This often sets it apart from statutory services, and can increase the uptake and acceptability of testing amongst marginalised groups. A qualitative study of community testing in Europe found that one of the key indicators of client satisfaction is having community-friendly staff who belong to or are close to the target community.[54]

CTPs should be proactive in recruiting members of the community to their staff and volunteer teams, and showcase this in recruitment and promotional materials. Delivering a peer-led service, where staff/volunteers are representative of the community they serve and include people living with HIV, has a number of advantages:

- Services are culturally competent and sensitive to the specific needs of the individual and community.
- Staff/volunteers understand and can address any cultural, religious, or linguistic barriers.
- Staff/volunteers may be more trusted by the community, reducing fear of stigma and judgement.
- Staff can utilise their personal and professional networks to access key groups.

52 NICE, 2016, HIV testing: *increasing uptake* (guideline NG60), *op. cit*
53 WHO, 2015, *Consolidated guidelines*, *op. cit.*
54 HIV-COBATEST, 2012, *Implementation of Community-Based Voluntary Counselling and Testing (CBVCT) Programs and Services. Qualitative study report* [https://www.aidsactioneurope.org/en/publication/implementation-community-based-voluntary-counseling-and-testing-cbvct-programs-and]

- Marginalised communities may not see themselves represented in clinical services and are therefore more responsive to peer-led interventions.[55]

Consulting people living with HIV in the design of services is essential, and recruiting them to conduct testing can be an effective way of challenging stigma and sharing lived experience.

Peer-delivery is not possible in every instance. Provided that staff develop thorough knowledge and understanding of the relevant community, services can be delivered in a way that is sensitive to their needs. Consulting and involving the community in the design of the intervention will support this. Guidance may also be available, such as HIV Prevention England's tips for providing a trans-friendly service.[56]

Staff members may have specialist knowledge by virtue of their lived experience. This knowledge should be shared within the organisation where possible so that a sole member of staff is not relied upon for knowledge around a particular group.

"It is also important to demonstrate that within the sexual health sector patients may have to interact with people who do not reflect their identity but are still able to deliver an excellent service based on compassion. Our staff team all identify as LGBT, but not everyone is cisgender and not everyone is male. When delivering testing we don't offer a choice of who specifically it is that you see because that's not something that would always be reflected in other services."

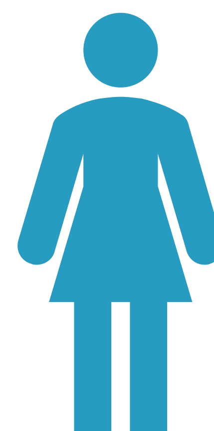
LGBT Foundation

Key attributes checklist

Staff/volunteers involved in the delivery of community testing should:

- ☐ Belong to or have a strong understanding of the target community
- ☐ Be sensitive to cultural and religious issues that may affect service users
- ☐ Be respectful of confidentiality and able to communicate this effectively to clients
- ☐ Be non-stigmatising and non-judgemental
- ☐ Be good listeners and effective communicators (CTPs should provide staff/volunteers with access to translation services and multilingual resources if necessary)
- ☐ Be able to discuss sensitive issues in a professional and compassionate way.

Clinical skills and knowledge required are covered in section C.2



55 Shangani S et al., 2017, 'Effectiveness of peer-led interventions to increase HIV testing among men who have sex with men: A systematic review and meta-analysis' *AIDS Care*, 29:8, 1003-1013
56 HPE, 2017, Briefing paper: 'Trans people and HIV testing' [https://www.hivpreventionengland.org.uk/evidence-and-guidance/hpe-briefings/]

C.2 Training and clinical governance

One barrier to implementing community testing has been a perception amongst some clients and commissioners that testing in community settings is substandard. This is despite community testing being recommended in national HIV testing guidelines. As a result, CTPs have worked hard to demonstrate the professionalism, quality and safety of their services. Two critical components of this are thorough staff training and robust clinical governance.

Clinical governance

Clinical governance is "the framework through which organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which clinical excellence will flourish."[57] In community testing, it ensures high quality services that are safe, well managed and accountable, regardless of where that service is delivered.[58]

Systems of clinical governance are complex, and we direct all commissioners and CTPs to the following resources for detailed guidance:

British Association for Sexual Health and HIV (BASHH), ***Standards for the management of sexually transmitted infections (STIs) in outreach services***, July 2016.[59]

British Association for Sexual Health and HIV (BASHH), ***Standards for the management of sexually transmitted infections (STIs)***, April 2019.[60]

Key responsibilities:

- Commissioners should ensure that requirements for governance and accountability are explicit in all contracts with providers of community testing services. Contracts must stipulate that a local specialist SHS supports the training of staff, assessment of competence, clinical supervision and ongoing maintenance of skills.
- CTPs should be able to demonstrate that effective clinical governance arrangements are in place and that services are safe and high quality. This includes:
  - Having a nominated clinical governance lead with responsibility for overseeing the clinical quality of the service
  - Using IT and managing information securely (in accordance with information governance and data protection policies), with protocols and standard operating procedures in place
  - A clear framework to support education and training that includes mentorship, clinical supervision and assessment of ongoing competence.

It should be noted that NICE explicitly recommends community testing in "venues where there may be high-risk sexual behaviour, for example public sex environments, or where people at high risk may gather, such as nightclubs, saunas and festivals."[61] We have heard that in spite of this, some clinical governance providers have been reluctant to countenance testing in such settings by lay testers.

Any concerns about outreach testing (for example potential intoxication or delays in referral) should be addressed within clinical governance arrangements but not preclude testing outright. This can otherwise seriously hinder the ability of CTPs to access people who may be at particularly high risk of acquiring HIV and for whom community-based testing is more acceptable. Good clinical governance and risk management can ensure that testing is safe and effective.

57 Department of Health, 2013, *Sexual Health: Clinical Governance* [https://www.gov.uk/guidance/commissioning-regional-and-local-sexual-health-services]
58 BASHH, *Standards for the management of sexually transmitted infections (STIs) in outreach services* [https://www.bashh.org/about-bashh/publications/sti-outreach-standards/]
59 *Ibid.*
60 [https://www.bashh.org/about-bashh/publications/standards-for-the-management-of-stis/]
61 NICE, 2016, *HIV testing: increasing uptake* (NICE guideline NG60), *op. cit.*

Case study: Clinical governance good practice when testing in bars and sex on premises venues (Yorkshire MESMAC)

Yorkshire MESMAC (YM) provides regular HIV testing in a variety of community settings including LGBT bars, gay saunas and other sex on premises venues. Each space they deliver testing in is assessed to ensure that at a minimum there is:

1) A confidential room where service users can't be seen or overheard with a table and two chairs.

2) A clear and safe entrance and exit from the space where people can leave without being observed.

Services are provided at times where people are less likely to be intoxicated, for example between 6-9pm. All testers are trained to ask questions about people's alcohol consumption, and to decline to test people deemed too intoxicated to test.

Testers are also trained to conduct pre-test discussions to help people prepare to manage a reactive result. For example, staff ask questions like "so you're on a night out with your friends and there's a chance that I might tell you that you may have HIV tonight, how are you going to feel about that? Have you thought about whether you might tell your friends? How might the news of a reactive test result affect what you do with the rest of your evening?" Service users can then make an informed decision, working on the principle that people are expert in their own lives and with the right information can choose to test at a time that's right for them.

YM has delivered reactive results in sex on premises venues. This has enabled people to be linked into treatment and care and prevented others from being put at risk. When testing in sex on premises venues YM always have two staff members present, one to deliver the test and one to promote the session and encourage others to test.

It may be that community testing is delivered at times that clinical services are closed. In the pre-test discussion YM always discuss with the service user how they are going to manage their test result in the period before being linked to care. Staff would decline to test those who disclose that they would not be able to cope with the wait. For those who opt to test on a Friday evening or at the weekend YM offer to text or call them to check in before their confirmatory test, and to signpost them to crisis services if they are struggling.

Training

How training is delivered depends on the clinical governance arrangements that are in place. In some instances training is delivered by staff from the specialist SHS, for example a health adviser or clinician. Alternatively, training can be delivered internally following agreed protocols.This may require senior members of the team to receive 'train the trainer' training from the specialist SHS. Other CTPs have developed their own training programmes, with support and approval provided by SHS. The CTP's level of testing experience may dictate which method is most appropriate.

All CTPs should offer face-to-face training, but may also utilise a 'workbook' or 'manual' to support and assess learning. This ensures that testers have a written resource to refer to in future.

After this initial training, testers often undergo a period of mentoring and supervision, involving mock-testing and observing others. This should take into account the settings that testing will take place in and the considerations specific to these. All trainees must then be observed in a live setting before being signed off as competent to test. This ensures that staff are confident and equipped to deal with the varied and challenging situations that can occur.

See the **Training checklist** on page 26, and the training and clinical supervision **Case study** on page 28.

Clinical supervision

Staff should have access to regular clinical supervision, either from the clinical governance provider or an approved internal clinical

Training checklist

Training should include a clinical component covering:

- ☐ Information on HIV including basic virology, prevention and treatment
- ☐ Standards of health and safety to be observed in all test settings
- ☐ Undertaking a sexual history and assessing risk
- ☐ Information about window periods and when to re-test
- ☐ Specimen collection, including practical demonstrations
- ☐ How to interpret and deliver results, and manage patients' reactions
- ☐ Referral pathways and linkage to specialist SHS
- ☐ Confidentiality and data governance
- ☐ Basic knowledge of other STIs.

Training should also provide preparation for the wider objectives of the intervention and must be relevant to the target community and local area. Topics include but are not limited to:

- ☐ Health promotion
- ☐ Methods of stigma reduction
- ☐ Pre- and post-test counselling
- ☐ How to discuss PEP and PrEP
- ☐ Chemsex and how to reduce associated risks
- ☐ Cultural competency, including barriers to testing that are specific to the target community
- ☐ Signposting to relevant local services including SHS, primary care, HIV support services, drug and alcohol services, domestic violence services and mental health services
- ☐ The importance of registering with a GP, and information on migrant health rights (see p.11)
- ☐ Policies and procedures to keep staff and volunteers safe in HIV testing settings. This may include a code of conduct and what to do in an emergency.

governance lead. This is an opportunity for staff to share best practice, raise issues or challenges that they have experienced, and learn about new developments related to HIV. Clinical governance providers may also conduct reviews, assessing ongoing competence and providing refresher training.

Some specialist SHS provide a direct line of communication to clinicians or health advisers. In the event of an emergency or unfamiliar issue, lay testers can access immediate clinical guidance.

Referral pathways

All CTPs must be able to demonstrate that clear referral pathways are in place with specialist SHS. These pathways should be established and agreed within clinical governance arrangements, and be understood by all testing staff. Processes for the secure sharing of information between different services should be in place, and these should be clearly explained to patients.

The process of referring clients to SHS will be covered in more detail in section E.2, but it should be noted that effective referral pathways can go in both directions. Many CTPs offer services that support people to prevent HIV, such as counselling or sexual health advice. **Some CTPs also offer HIV support services, and SHS should be proactive in referring clients with positive confirmatory results back to CTPs in this instance for support.**

Referral pathways should also be in place for other relevant local services (See section E.2.2)

Key considerations for commissioners and clinical governance providers:

- As CTPs are client-centred, patients may be referred to a clinic of their choice if the local SHS is not suitable. This is good practice, but pre-established referral pathways may not be in place with all local clinics. To ensure that pathways for patients are seamless, all SHS could have a direct line specifically for fast-tracking reactives from community settings.
- Clinical governance providers should be supported to understand the contribution that community testing makes locally in preventing and reducing HIV. Fundamentally, SHS need to recognise that the community testing model can be safe and high quality. Specialist SHS must be contracted to support CTPs by providing appropriate clinical governance that allows providers to offer flexible and high-quality services in accordance with NICE guidelines.
- Clinical governance documentation should be streamlined and suitable for a lay audience. Clinical governance providers should be aware that protocols have the potential to be inaccessible to staff without clinical backgrounds. Ensuring safety and professional standards is paramount, and protocols should be written in a way that best enables this.

C.3 Quality assurance

Quality assurance refers to planned activities that ensure the intervention meets high standards of quality. This means providing accurate test results and delivering services according to established procedures. Training and clinical supervision are core elements of quality assurance, as are processes of quality control, quality improvement, and wider monitoring and evaluation.

To ensure that quality assurance takes place and that learning and improvement occurs, quality assurance should be built in to the costing and delivery of the intervention. This should take into account the staff time required to manage this process. CTPs should also develop a quality assurance plan encompassing the various elements of the intervention. This will support staff/ volunteers and instil confidence in the intervention.

To support quality assurance we recommend that CTPs use the following resources:

World Health Organisation, ***Improving the quality of HIV-related point-of-care testing: ensuring the reliability and accuracy of test results,*** 2015[62]

- Detailed guidance on how to integrate quality assurance into the planning, implementation and evaluation of rapid HIV testing. Includes examples of quality improvement checklists, standard operating procedures, and quality control assessments.

World Health Organisation, ***Consolidated Guidelines on HIV Testing Services - 5 Cs: Consent, Confidentiality, Counselling, Correct Results and Connection***, 2015[63]

- See *Chapter 8: Quality Assurance of HIV Testing* for guidance on the different components of quality management systems including Process Control and Information Management.

HIV-COBATEST, ***A guide to doing it better in our CBVCT centres,*** 2017[64]

- See *Chapter 3.7: Monitoring and evaluation of CBVCT* for a quality assurance framework and *Appendix 2* for a practical self-evaluation tool.

National AIDS Trust, ***Community HIV Testing: Evaluation Toolkit***, 2020[65]

- Provides guidance on data collection and suggests a range of indicators that can be used to support monitoring and evaluation.

62 [https://www.who.int/hiv/pub/toolkits/handbook-point-of-care-testing/en/]
63 [https://apps.who.int/iris/handle/10665/179870]
64 [https://cobatest.org/conferences-and-publications/]
65 [https://www.nat.org.uk/nat-topic/community-testing]

Case study: A training and clinical supervision programme for volunteer testers (Positive East)

Positive East ensures a high standard of professionalism through a robust selection and training process for staff and volunteers. This has been developed in partnership with the clinical governance provider.

The training model for volunteer testers is as follows:

- Volunteers must first do 3 months of outreach work so that they understand the role and so that Positive East are able to do an initial assessment of their suitability.
- Positive East will then conduct a screening interview to check that they are ready; many volunteers are service users living with HIV and it is important to consider the impact that delivering a reactive result might have on them.
- After the screening interview Positive East deliver a full day of training in partnership with Barts NHS Trust's health advisor training team.
- Volunteers are also provided with a clinical governance manual containing information about HIV and other STIs that Positive East screen for and all of the referral pathways in the local area (including SHS, domestic violence units, chemsex services, etc). Volunteers must then complete a written assignment to test their knowledge of this information.
- After passing the written assignment volunteers must observe 3 sessions of testing, and then be observed delivering 3 testing sessions themselves. Each session is 3 hours long. Trainers may deem it necessary for further observation to take place before volunteers can be signed off, and there is no maximum number of observations.

Once a volunteer is signed off to test, every 2 months they are required to attend a 2-hour clinical supervision session where examples of best practice and challenging situations are shared. These sessions are also an important opportunity to provide training on any new information relevant to HIV testing. For example, all testers have received top-up training on PrEP and how to refer clients onto the PrEP Trial via the clinical governance provider's PrEP team.

Should any issues arise during testing that require external support, Positive East can contact clinicians or health advisers from the clinical governance provider who can provide immediate guidance and/or refer clients straight into the clinic if necessary.

D. The test itself

D.1 Types of test

There are several types of HIV test available in the UK that fall into two main categories:

Laboratory tests

These tests all involve a sample being sent to a laboratory for analysis:

- **Blood test** – a blood sample is taken through a needle from a vein and sent to a laboratory. Results are usually available within a few days.
- **Dried blood spot** – a sample is taken by pricking a finger and collecting drops of blood on a special card (filter paper). Once dry, the card can be sent to a laboratory for analysis.
- **Self-sampling kit** – the user collects a saliva or blood sample at home and sends it off in the post for testing. Results are available within a few days.

Rapid tests

These tests provide results in a short period of time at the same location that the test is conducted:

- **Point of care test** (POCT) – a sample of saliva from the mouth or a small spot of blood from the finger is taken by a trained practitioner. The result is available within a few minutes.
- **Self-testing kit** – the user collects a small blood sample themselves and tests it at home. They then interpret the result which is available within 30 minutes.

National guidelines for HIV testing support the use of point of care tests (POCT) in community settings.[66] This is because they do not require venepuncture, and results are available almost immediately. Self-testing kits share these advantages, and both of these test types are described as rapid tests. An obvious benefit of community testing compared to self-testing is that you receive the result in the company of a trained tester who can provide immediate support.

Crucially, rapid tests should be used for screening only. Results from rapid tests are either reactive, non-reactive or indeterminate:

- **Reactive results** indicate the presence of HIV, however they are only preliminary and must be promptly followed by confirmatory blood tests in a clinical setting.
- **Indeterminate results** are unclear, and should be promptly followed by confirmatory blood tests in a clinical setting (see section E.2.1)
- **Non-reactive results** mean that the test did not find any evidence of HIV infection. This can be relied on provided that there is no risk that HIV has been acquired during the test's window period (see below).

With regards to POCT, the British Association for Sexual Health and HIV (BASHH) stipulates:

"Where possible HIV POCT should be a 4th generation test (detecting both HIV 1 and 2 antibody and P24 antigen), however in certain outreach settings a 3rd generation (HIV 1 and 2 antibody only) test may be used either on its own or for example in combination with a syphilis test."[67]

At the time of writing the main categories of POCT are 3rd generation and 4th generation tests. Each category differs as to what it tests and the time a patient has to wait for their results:

- **4th Generation** - these test for HIV antibodies and p24 antigens. Results are ready in 10-20 mins.
- **3rd Generation** - these test for HIV antibodies only. Results are ready in 1-20 mins.

P24 antigens can be detected sooner than HIV antibodies, so 4th generation tests should be better at detecting HIV in the earlier stages of infection. This is true of laboratory tests: 4th generation laboratory tests reliably detect HIV within 45 days of exposure, compared to within 2 months for 3rd generation laboratory tests.[68] This period of time,

66 BHIVA, BASHH & British Infection Society (BIS), 2008, *UK National Guidelines for HIV Testing 2008* [https://www.bhiva.org/HIV-testing-guidelines]
67 BASHH, 2016, *Standards for the management of STIs in outreach services, op. cit.*
68 Delaney KP et al., 2017, Time Until Emergence of HIV Test Reactivity Following Infection With HIV-1: Implications for Interpreting Test Results and Retesting After Exposure' *Clin Infect Dis*. 64(1):53-59

between infection and reliable detection, is known as the window period. Because POCTs test blood from a fingerpick rather than blood that has been separated out in a laboratory, the window period of POCTs may be a week or two longer.[69]

It is important to verify that any test used is CE-marked. This means that the test conforms to European health and safety legislation. It is also important to consider the accuracy of tests. While POCTs are not equal in accuracy to laboratory tests, data available for tests commonly used in the UK is encouraging. A WHO evaluation of tests commonly used by CTPs found that all had a sensitivity (the ability to detect all true positive results) and a specificity (the number of negative samples correctly identified as negative) in the range of 99-100%.[70]

False positives (results that say HIV is present when it is not) may however be a problem if testing populations with a low prevalence of HIV. Tests always produce a small number of false positives, but the proportion of false positives becomes much greater in populations where very few people have HIV.[71] POCT is therefore more appropriate when testing key populations.

All CTPs spoken to in the course of producing this toolkit predominantly use POCT. The vast majority use blood-based tests because of oral fluid's slightly poorer performance and longer window period.[72] However, oral fluid (taken using a mouth swab) can be more acceptable to some people and in certain settings, as can receiving results at a later date (e.g. using a dried blood spot test) rather than at the time of testing. Universities for example have been reluctant for students to receive results on the premises, while some venues do not like the idea of blood testing on site. Using a combination of tests may therefore facilitate access to a wider population.

CTPs should consult the local sexual health clinic or laboratory for advice on training, interpretation of results, trouble shooting, quality control and health and safety. The manufacturers of each test kit can also provide training to CTPs on how it should be used.

Key considerations when determining test type:

- **Context –** the acceptability of the test in different settings and to different people must be considered. Some tests may be more appropriate in certain settings than others; offering different tests in different settings can increase access to the target population.
- **Window period –** this is the period of time between infection and the point when the test will give an accurate result. Tests with a shorter window period are therefore more likely to detect HIV in individuals with recent infection and support earlier diagnosis.
- **Accuracy** – the use of accurate tests is vital to ensure that HIV is correctly diagnosed and to instil confidence in staff/volunteers and service users.
- **Speed of results –** the time taken to get results varies amongst POCTs from 1 to 30 minutes. Some CTPs have found that a longer wait is not feasible, whereas others find a longer waiting time useful to conduct counselling or other health promotion. CTPs should therefore choose according to the model they are delivering.
- **Advice from other services –** local SHS and clinicians should be able to provide advice on the suitability of different tests. Other CTPs may also have insight into the advantages and disadvantages of different tests in community settings. Some clinicians and CTPs have done extensive assessments and investigations to find the best option.
- **Preparation –** some tests are easier to prepare and have less wastage than others. Disposal of waste materials may be problematic in some settings. With the approval of local sexual health leads, CTPs may wish to trial multiple test kits.
- **Cost –** the financial cost of different test kits will be a consideration for CTPs. That said, minimum standards must be met and the suitability of the test should be prioritised.

69 HPE, 2019, 'HIV testing technologies' [https://www.hivpreventionengland.org.uk/evidence-and-guidance/hpe-briefings/]
70 *Ibid.*
71 NAM provides useful information about false positives, test accuracy and window periods [https://www.aidsmap.com/topic/testing-health-monitoring]
72 HPE, 2019, 'HIV testing technologies' *op. cit.*

Self-testing in the community – the community coaching model

Some CTPs have experimented with the use of self-testing or self-sampling kits rather than traditional POCT. This has been described as a community coaching model. In this model a member of staff will introduce and demonstrate the self-test kit so that the client understands how to use it, building their confidence and resilience so that in future they can test themselves. This can empower people from high-risk populations to manage their own sexual health and negotiate the different services available to them. It is particularly important if using this model to ensure that individuals know what support is available from CTPs and when to seek professional help or advice.

D.2 Testing for other STIs

Although many CTPs test exclusively for HIV, an increasing number are providing a wider STI screen.[73] Most commonly offered alongside HIV tests are tests for Gonorrhoea, Chlamydia and Syphilis. Some CTPs have also offered testing for Hepatitis B and C. The European Centre for Disease Prevention and Control have advocated for integrated testing for HIV and viral hepatitis, including target groups in community settings.[74]

For Gonorrhoea and Chlamydia, all CTPs consulted by NAT use three-site (oral, rectal, vaginal) swab testing due to its ease of use and relevance to the types of sex practised by MSM. For Syphilis and Hepatitis, point of care testing tends to be used due to the immediacy of results; some point of care tests are able to test for HIV and Syphilis at the same time. CTPs should only test patients who are asymptomatic. Symptomatic patients should be referred to SHS or their GP and supported to attend.

Benefits of integrated STI testing

- People who are not accessing SHS may be at increased risk of other STIs as well as HIV. Not testing for other STIs can therefore represent a missed public health opportunity.
- It reduces the exceptionalism of HIV and can make testing more acceptable to people who are reluctant to test for HIV alone.
- It supports people to manage their sexual health more broadly as part of a personal sexual health strategy.
- While HIV diagnoses have decreased in recent years STI diagnoses have increased, so CTPs can utilise their existing services to tackle this problem.
- Some CTPs that offer STI testing have reported positivity rates for STIs that are higher than those seen amongst asymptomatic clients in local SHS.

Challenges to integrated STI testing

- More staff time, knowledge and training is required. Capacity for this may not be available.
- CTPs who deliver STI testing are not all commissioned to do so and some are having to fund this themselves. This may not be a sustainable model for voluntary sector organisations.
- There may be concerns about the accuracy of rapid tests for other STIs that will need to be considered.

Key considerations for CTPs and commissioners

- CTPs should assess the need for further STI testing as part of the process of assessing risk behaviours with patients. Symptomatic patients should be referred to SHS.
- Commissioners should consider the benefits of community-based STI testing, especially in areas of higher need. Where CTPs are already delivering STI testing, commissioners should review positivity rates and consider integrating this into contracts.

73 In 2018, 50% of CTPs offered HIV testing alongside screening for other STIs (Data received as part of a data request from Public Health England, January 2020)
74 ECDC, 2018, *Public health guidance on HIV, op. cit.*

E. Before and after the test

An HIV test is a medical procedure with significant implications, and it is important that certain steps are followed before and after the test itself. The exact process will vary in different contexts, but as a general principle WHO recommends that:

"HIV testing must always be done with informed consent, adequate pre-test information or counselling, post-test counselling, protection of confidentiality and referral to services."[75]

The following section is informed by the experience and expertise of the CTPs consulted by NAT, as well as guidance produced by the World Health Organisation, the European Centre for Disease Control, and the HIV-COBATEST project.[76]

E.1 Pre-test: information and counselling

In this context, counselling refers to the provision of advice and support. It does not require that the staff member/volunteer is a qualified counsellor or psychotherapist.

The minimum level of pre-test discussion is low. In the UK, national guidelines for HIV testing stipulate that:

"The primary purpose of pre-test discussion is to establish informed consent for HIV testing. Lengthy pre-test HIV counselling is not a requirement, unless a patient requests or needs this."[77]

This approach, as the guidance notes, is successful and acceptable in clinical settings. It removes a potential barrier to testing and increases the efficiency of the service. This is also true of community testing. However, as community testing often serves those at increased risk or with complex needs, staff should be prepared to provide in-depth information and counselling if required.

Consent

HIV testing is a voluntary procedure, and it is imperative that clients provide informed consent to being tested. Verbal consent is sufficient; written consent is unnecessary and may actually discourage HIV testing.[78]

To give informed consent clients must understand what the test involves, how results will be given, and what the results mean. If a client declines to test their decision must be respected, but the reasons for their decision should be explored.[79] CTPs report high levels of HIV stigma and misinformation amongst their clients, and this may be an opportunity to address incorrect beliefs.

Many clients presenting in community settings may not speak English as their first language, so it is important to make sure they clearly understand what they are consenting to. Staff should be able to access multilingual resources or translation services in this instance.

There may also be circumstances where a client wants to test but it is not appropriate to test them. This could be due to concerns about the client's state of mind, or because of practical issues such as capacity. Such circumstances should be clearly defined and protocols put in place to manage them.

Confidentiality

The principle of confidentiality is central to healthcare, and is of particular relevance in this context. HIV remains a highly stigmatised condition and clients must be assured that their decision to test and anything that is discussed will not be disclosed to anyone without their express consent. Exceptions to this, such as where disclosure is deemed necessary for safeguarding reasons (all CTPs must have an agreed safeguarding policy in place), should also be communicated to the client.[80] Clients may need reassurances about

75 WHO Europe, 2010, *Scaling up HIV testing and counselling in the WHO European Region* [http://www.euro.who.int/en/health-topics/communicable-diseases/hivaids/publications/2010/scaling-up-hiv-testing-and-counselling-in-the-who-european-region.-policy-framework]
76 WHO, 2015, *Consolidated guidelines, op. cit*.; CDC, 2017, *Implementing HIV Testing in Nonclinical Settings: A Guide for HIV Testing Providers* [https://www.cdc.gov/hiv/testing/nonclinical/index.html]; HIV-COBATEST, 2017, *A guide to do it better in our CBVCT centres, op. cit.*
77 BHIVA, BASHH & BIS, 2008, *UK National Guidelines for HIV Testing, op. cit.*
78 *Ibid.*
79 *Ibid.*
80 For information about patient confidentiality see: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/disclosures-for-the-protection-of-patients-and-others and https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice

how their information will be stored and who will be able to access it; this should be covered by CTPs' GDPR arrangements and be easily relatable to clients.

People presenting in community settings may also have concerns about their personal information being shared with SHS - for example, those with insecure immigration status. Clients should therefore be assured that SHS are also confidential services. If this remains a concern, clients should be informed that they are able to test anonymously using a false name, and that the same applies to SHS should they be referred. To ensure that anonymous testing doesn't result in clients dropping out of the system, the benefits of treatment must be made especially clear

Counselling

One area in which community testing often differs from clinical testing is in the length and depth of counselling that can be provided. As we know, people testing in community settings often don't access clinical healthcare but may be at higher risk of HIV. Testing provides an opportunity to engage in dialogue with these individuals about their health and wellbeing and to support sexual health promotion.

Counselling should be client-centred with the extent being informed by risk and need. Lengthy counselling can be a barrier for some and could undermine benefits of speed and convenience, so the process should never be more extensive than necessary.

Counselling may also need to be adapted to the specific environment, as some settings will afford a lengthier interaction than others.

On the following page is is a list of topics (in no particular order) that should be covered during the counselling process. How this information is covered is at the discretion of individual CTPs. Typically clients will be asked to complete a registration form, and testing staff will then follow a discussion checklist to direct the conversation. Some CTPs use the client registration form only to collect personal details (such as contact details, ethnicity, and sexuality), whereas others use the registration also to assess need; this preliminary assessment can then inform the content of the conversation. If the test results are ready in 10-20 minutes some of the discussion could take place during this waiting period. This may reduce potential stress and anxiety on the part of the client.

E.2 Post-test: results and referrals

This section is directly applicable to CTPs that offer POCT and can therefore deliver results at the time of testing.

Where CTPs offer dried blood spot testing or use self-sampling kits, the results will instead be communicated directly to the client by the relevant laboratory. In these circumstances, CTPs should refer clients to other services relevant to their needs (see section E.2.2 Referrals), and then later attempt to follow up with clients about their results. Staff/ volunteers may then pursue the relevant actions below.

E.2.1 Results

When the result is ready, the tester or another trained member of staff will read and interpret the result. As most community testing is POCT, results can normally be given face-to-face. In the event that the client is not present to receive the result, how it is delivered will depend on the result itself and this should be discussed at the time of testing. If the result is reactive, the client should be invited to receive it in person unless they request otherwise. If it is not reactive, clients can be given the results by telephone but should be invited in to discuss further support if necessary.

Regardless of outcome, the result should be conveyed to the client in a clear and direct manner, with particular consideration given to clients for whom English is not a first language. Space should be given for the client to process the result, express their emotions, and ask any questions. Post-test counselling must always be client-centred and tailored to the specific needs of the individual.

Non-reactive results

Where results are not reactive post-test counselling can be brief. Key issues that the post-test discussion should cover are:

- When the client should test again
  - See NHS guidance on how frequently different populations should test[81]

81 [https://www.nhs.uk/conditions/hiv-and-aids/diagnosis/]

Counselling checklist

- ☐ The benefits of HIV testing to the individual and the community.
- ☐ The meaning of reactive, non-reactive and indeterminate results, including:
  - The window period and when to re-test if necessary
  - The need for a confirmatory test at a clinic in the event of a reactive result
  - The possibility of false positive results, and who is more likely to receive them.
- ☐ An assessment of HIV risk:
  - Reason for testing and expected result
  - Sexuality and type of sex practised
  - Testing history (this could include other STIs)
  - Sexual history - identifying potential exposures to risk and frequency including:
    - Unprotected sex (with HIV+ partners, partners of unknown status, partners from high prevalence countries)
    - Buying or selling sex
    - Non-consensual sex
  - Other risk behaviors such as injecting drug use and chemsex.

    Note: Clients should be swiftly referred to relevant agencies according to agreed protocols. This may include SHS (for PEP or full STI screening), drug and alcohol services, mental health services, and sexual assault referral centres.
- ☐ HIV prevention and sexual health promotion
  - An assessment of the client's knowledge of HIV and wider sexual health
  - Advice on HIV prevention strategies and safer sex, including information about condom schemes, PEP and PrEP
  - Recommended frequency of testing for HIV and other STIs
  - Common symptoms of seroconversion to be aware of.
- ☐ Services available in the event of a reactive result and positive confirmatory test
  - HIV treatment and care
  - HIV support services (these may be provided by the CTP)
  - Partner notification processes
    - If the client has had unprotected sex in the last 72 hours, a PEP referral for the partner may be recommended.
- ☐ OPTIONAL: Wider health and wellbeing
  - Drug and alcohol assessments and referral to relevant services.
  - Mental health evaluation and referral to relevant services.

Some of the above could be delivered after the results have been received and might be framed differently depending on the result. CTPs should consider the needs of the individual and what is most appropriate in a given environment. For example, regular testers will not require the same level of information as someone testing for the first time.

- Where else testing is available
  - Provide client with details of all options available, including online testing
- How to remain HIV-negative – i.e. HIV prevention strategies
  - If this has been covered in the pre-test counselling a brief summary will suffice
- Continuing support available, and linkage to relevant services
  - See section E.2.2.

Indeterminate results

An indeterminate result means that the test result is not clear. This may be because the client is in the early stages of HIV infection (the window period) and therefore the test is unable to detect HIV conclusively. Alternatively, it may be the result of a technical error or because of a reaction to other antibodies not related to HIV. These possibilities should be explained and clients should then be swiftly referred to SHS for confirmatory testing (see section E.2.2).

Clients who receive an indeterminate result are likely to be anxious about the possibility that they have HIV. Testers should seek to manage this anxiety but also be clear about the importance of attending the confirmatory test, highlighting the benefits of early diagnosis and treatment.

Reactive results

Where results are reactive clients will likely need significant support. Advances in treatment have made HIV a manageable condition, but an HIV diagnosis is a still a life-altering event. It is important that clients are given time to process the result and express any emotions that may arise. Clients who are in a state of shock may find it difficult to process further information, so staff should first provide space and emotional support. Once the client is ready, the following steps should be taken:

- Emphasise the benefits of knowing your HIV status in order to begin treatment as soon as possible. Remind the client that treatment allows people with HIV to live long, healthy lives.
- Explain the need for a confirmatory test, and offer to refer the client directly (see section E.2.2). If a client declines to be referred, provide information about local SHS and encourage them to refer themselves as soon as possible.
- Establish what support mechanisms the client has access to, such as friends and family. This can be very important during the period between the reactive result and confirmatory test.
- Inform clients about partner notification (PN) services provided by SHS. This is a voluntary process, but the benefits of PN should be explained and clients should be assured that the process is anonymous and that they will be fully supported.
- Provide information about how to prevent transmission of HIV to others, including condom use, the effect of an undetectable viral load, and the use of PrEP by sexual partners. In the case of people who inject drugs, information should also be provided about needle exchange programmes.
- Provide information about local HIV support services and how to access them in the event of a positive confirmatory test (see section E.2.2).
- Assess the impact of the result on the client's mental health and wellbeing, and refer them to relevant services if necessary.

E.2.2 Referrals

It may be necessary to signpost or refer clients to other services. Signposting involves providing a client with the necessary details to approach another service themselves. Referrals involve directly facilitating contact between the client and another service. This may be done either by passing the client's details (with their consent) to another organisation who will then contact them; making contact with another organisation on behalf of the client and arranging an appointment; or physically accompanying the client to another organisation.

Non-reactive results

During the counselling session the client will provide information that may indicate the need for further services. Some clients may not require any further support, while others may have extemely complex needs. The ability to respond to these

needs and deliver a client-centred service is central to effective community testing.

Staff should identify services that are appropriate to the client's needs. In the case of clients with non-reactive results, relevant services may include:

- Sexual health services (for PEP, PrEP, full STI screening, and contraception)
- Condom schemes
- Mental health services
- Drug and alcohol services
- Migrant, refugee and asylum services
- Domestic abuse services
- Sexual assault referral centres
- GPs (for clients with wider health issues and clients who are not registered).

Some of these services may be provided by CTPs themselves, in which case an internal referral may be made. For external services, CTPs should determine whether signposting or referring clients is most appropriate, and provide support accordingly.

The list of services above is not exhaustive and referrals will depend on the specific needs of different populations and individuals. CTPs should consider the types of services their clients may require and develop relationships and referral pathways accordingly. Where there are not agreed pathways in place, staff can still support clients to access these services by contacting services on their behalf or helping clients to refer themselves.

Indeterminate results

Clients who receive indeterminate results should be promptly referred to SHS for confirmatory testing (see Reactive results below). They may also require referrals to other services relevant to their needs (see Non-reactive results above).

Reactive results

Ensuring linkage to prevention, treatment and care services is fundamental to effective HIV testing. In the case of community testing, clients who receive a reactive result must have a confirmatory blood test in a clinical setting. If this test confirms that the client is HIV-positive, the client can immediately begin receiving treatment and care. It is therefore imperative that clients have a confirmatory test as soon as possible in order to protect their health and the health of others.

To facilitate this, CTPs are required to have seamless referral pathways in place for the swift transfer of clients into SHS.[82] These referral pathways are unique to CTPs and determined by the clinical governance arrangements in place. A standard operating procedure should be followed, and although this will differ between CTPs the key elements of this process are largely the same:

1) Gaining consent to refer the client

After explaining the need to have a confirmatory test, CTPs should ask the client if they can refer them immediately. Some CTPs ask for clients to consent to this before the test itself, but others consider this a potential barrier to testing. If the client declines to be referred immediately the importance of the confirmatory test must be emphasised and the process of self-referral clearly explained and understood.

Clients should be offered further support if they do not feel ready for a confirmatory test, and signposted to relevant services.

2) Referring the client to SHS

CTPs must have agreed referral pathways in place with one or more local SHS. Typically, this process involves CTP staff having a direct line to clinicians or health advisers who are able to book in the client for a blood test. Other arrangements include emailing a designated inbox which is monitored by the SHS on a daily basis. Lines of communication should be secure and where relevant encrypted.

The advantage of telephone referrals is that the appointment can be arranged while the client is still present, and appointments are often on the same day. When community testing is delivered outside of SHS opening hours the client should be referred the following morning. Regardless of the process, confirmatory tests should be conducted within 48 hours, and sooner if possible. This is in line with current practice and national standards.[83]

As referral pathways are determined by clinical governance arrangements, CTPs will have clear pathways in place with the sexual health service that provides their clinical governance. However,

82 BASHH, 2016, *Standards for the management of STIs in outreach services, op. cit.*
83 *Ibid.*

CTPs are client-centred, and some clients may wish to be seen in a different SHS. Staff should therefore have a good knowledge of other local SHS and offer to refer clients to the SHS of their choice. This is particularly relevant in major cities where outreach testing may be delivered across large geographical areas. In this instance it may be most convenient for clients to test at the nearest SHS to the test setting, and so some CTPs notify the nearest SHS in advance of testing.

3) Supporting the client to attend the confirmatory test

It is good practice to offer to accompany the client to their confirmatory test. This may be possible immediately after the reactive test or at a later time, depending on the availability of appointments. Accompanying the client enables CTP staff to provide emotional support and manage concerns about attending a SHS and the fear of potentially receiving a positive result. In the case of non-English speaking clients, staff may also be able to provide linguistic support.

If clients do not wish to be accompanied, staff should talk through the process so clients know what to expect. Staff must also ensure that clients know where and when their appointment is, and how to get there.

4) Follow-up and ongoing HIV support

Follow-up is an important part of this process in order to ensure that clients do get a confirmatory test and are provided with any further support that they need. Consent to follow up with the client should be discussed during pre- or post-test counselling, and where possible follow-up should be conducted by the same member of staff who conducted the initial test.

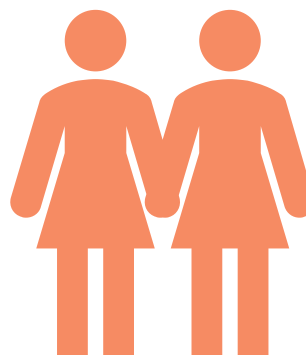
Although the majority of CTPs follow up with the client, some CTPs have data sharing agreements in place which allow them also to follow up directly with the SHS. These agreements can cover clients' attendance, confirmatory test results, and CD4 count. This enables CTPs to target follow-up accordingly and chase those who do not attend the confirmatory test. If such an agreement is in place it must be clearly communicated to the client and consent must be provided. One major benefit of being able to access clients' CD4 count is that it enables CTPs to measure late diagnosis. This can help CTPs to evaluate and demonstrate their impact.

In addition to monitoring test attendance, client follow-up is important to ensure that clients have access to ongoing support. Clients who test HIV-positive may need specialist support beyond that provided in generic or clinical services. This may include counselling and peer-support, and is provided by HIV support services. This support is particularly important during times of significant need such as when newly diagnosed.

Many CTPs are themselves HIV support services, and can therefore refer the client into in-house support services. If this takes place at the time of the reactive result, support will be dependent on the outcome of the confirmatory test. CTPs that do not provide HIV support themselves should establish relationships with local HIV support services that do, in order to refer clients at the point of diagnosis or immediately following the reactive result. Clients are under no obligation to continue their relationship with the CTP or receive further support, but it is important that they aware of what support is available should they need it.

5) Referrals to further services

In addition to HIV support services, clients may require the support of other medical, social and behavioural services. Staff should identify these during counselling and refer clients accordingly. See Non-reactive results above for some of the potential services clients may require.



Intervention design: Summary points for CTPs

Who to test

- Use data collected by Public Health England and work closely with commissioners to share intelligence and develop a strong understanding of local need.
- Review this data on at least an annual basis to ensure that understanding is up to date.
- Population categories (e.g. Black African adults) reported in the data are not homogeneous groups; consider additional local context to add value to this data.
- Learn from the service as you go; use further data collected during testing (see NAT's *Community HIV testing: Evaluation Toolkit*) to identify subsets of the target population/s at particular risk.
- Establish a clear policy on who is eligible to receive a test, considering your objectives, capacity and funding.
- Direct commissioners to the list of 'Key considerations for commissioners' (see section A.2) and encourage them to involve you in the setting of any targets.

How to engage people

- Identify suitable locations to conduct testing, considering both in-house and outreach settings.
- Choose locations where the target population/s will be found and where they will feel most comfortable, involving members of the relevant population/s in this process.
- Provide a range of opening times in order to be convenient for as many people as possible, for example by offering testing in the evenings and/or at weekends.
- Develop and maintain positive relationships with stakeholders who provide access to outreach settings.
- Ensure that all settings meet the criteria in the **Accessibility checklist** on p.17.
- Consider the range of recruitment methods detailed in section B.2 and develop a holistic recruitment strategy that enables maximum engagement with the service.
- Adapt recruitment methods to the needs of the target population/s, giving attention to the various subsets within population groups.
- Review each of the actions in the **Recruitment checklist** on p. 21.

Staff, training and clinical governance

- Decide who will conduct the tests. Beyond staff members, consideration should be given to the use of volunteers and collaboration with staff from local SHS.
- Recruit members of the target population to become lay testers. This will enable the delivery of peer-led services (see section C.1).
- Consult people living with HIV in intervention design and support them to become lay testers.
- Ensure that all staff/volunteers are culturally competent and sensitive to the needs of individuals and the community. See **Key attributes checklist** on p. 23.

- Provide comprehensive clinical training to all testing staff/volunteers (See **Training checklist** on p. 26.), and ensure that staff/volunteers have access to regular clinical supervision with support from specialist SHS.
- Meet all key clinical governance responsibilities stipulated by BASHH and agreed with local clinical governance providers (see section C.2).
- Ensure that clear referral pathways are in place with specialist SHS.
- Direct commissioners and clinical governance providers to **Key considerations for commissioners and clinical governance providers** on p. 31.
- Guarantee high standards of quality by building quality assurance into the design of the intervention (see section C.3).

The test itself

- Consider which type of HIV test (POCT, self-sampling, etc) is most appropriate to the model of community testing being delivered.
- Research the different testing kits available and identify which best meets your needs and the needs of the target population/s (see **Key considerations when determining test type** on p. 30).
- Consult clinical governance providers in the process of choosing a test, as well as for advice on delivering the test, interpreting results, and health and safety.
- Ensure that any testing kit used is CE-marked and approved by the clinical governance provider.
- Consider whether testing for other STIs is feasible and would add value, and if so seek funding to deliver this (see section D.2).

Before and after the test

- Explain that testing is voluntary and ensure that clients are able to provide informed consent to test. Explore the reasons for any decision not to test.
- Emphasise that confidentiality is central to the service and address any concerns.
- Provide client-centred information and counselling before and/or after the test (see **Counselling checklist** in p. 34). This should be informed by individual need and should not be more extensive than necessary.
- Deliver test results clearly and calmly, explaining the meaning of the result and allowing clients time to process this and ask any questions.
- In the case of non-reactive results:
  - Ensure that clients know when to next get tested and how to remain HIV-negative.
  - Provide information about further support available, and offer to refer clients into other services relevant to their needs (see section E.2.2).
- In the case of indeterminate or reactive results:
  - Provide information about treatment, living with HIV, local HIV support services, and how to prevent transmitting HIV others.
  - Discuss support mechanisms, partner notification, and mental health and wellbeing.
  - Swiftly refer clients into local SHS for confirmatory testing following the steps in section E.2.2
  - Assess wider needs and make referrals accordingly.

SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

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