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# An Evaluation of HIV Self Test Scotland J Hirono, R McKenna, R Hughes, N Sparling

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## Introduction

HIV testing is a critical first step in HIV prevention, treatment, care and support. The World Health Organisation (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) strongly recommend the scale up of HIV testing services as a crucial determinant to achieving the global UNAIDS 90-90-90 targets, where 90% of people living with HIV know their status, 90% of those diagnosed are on treatment, and 90% of those treated achieving viral suppression (UNAIDS, 2014). Given this call to action, countries all over the world have committed to realising these global targets.

Scotland has made significant progress in addressing HIV transmissions through its Sexual Health and Blood-Borne Virus Framework (*the* Framework), which sets out a high-quality and coordinated response to HIV. The ambitious targets outlined within the Framework have guided Scotland's efforts to significantly reduce the transmission of HIV and improve rates of diagnosis and treatment. This includes the promotion of HIV testing across all NHS services that engage with those at higher risk of HIV and expanding testing in non-traditional settings (The Scottish Government, 2015). The Framework has provided a strong foundation for Scotland's HIV response and played a critical role in positioning Scotland to exceed and maintain the global 90-90-90 HIV targets.

In particular, the Sexual Health and Blood-Borne Virus (SHBBV) Framework executive leads and chairs of the SHBBV National Networks identified HIV testing as a priority back in 2017. They commissioned the work of the Short-Life Working Group on HIV Testing which published the HIV Testing in Scotland report (HIV Scotland, 2018). The report recommended that HIV self-testing options be made available to those unable to undergo testing due to capacity issues experienced by health systems and to commission a research pilot for selftesting be developed to provide free, at-home testing for key populations. In light of these recommendations, HIV Scotland and Waverley Care launched HIV Self Test Scotland, a free, at-home HIV self-testing service for Scotland.

Today, Scotland has exceeded international HIV targets: Scotland began 2020 with an estimated 6,122 people living with HIV (PLHIV) in Scotland. Of those, 92% have been diagnosed, 98% of people diagnosed are receiving HIV treatment and 95% of those on treatment have achieved an undetectable viral load. Despite this, HIV continues to be a major public health concern in Scotland. Despite being over 30 years into the HIV epidemic and with widespread availability of highly effective treatment, 8% of those living with HIV are unaware of their positive status, representing an estimated 500 people who remain undiagnosed (Health Protection Scotland, 2020).

Lack of HIV testing can be attributed to structural barriers to obtaining an HIV test (e.g. capacity, time constraints), lack of knowledge about how to obtain a test, low perceived risk of HIV infection, and individual psycho-social issues, such as fear of a positive test result, or issues around disclosure (Rodger, et al., 2020) (Hirono, 2018). It is also important to note that residing in rural, regional, or remote areas of Scotland has the potential to discourage individuals from reaching HIV testing services, where accessing sexual health services in these areas may potentially incur substantial social and economic costs. For example, accessing rural HIV testing services may inadvertently expose HIV status by merely accessing the service, resulting in the loss of anonymity and the possible production of negative or unwanted attention. Should testing service be located afar, the resulting cost of transportation or loss wages would be important factors which may also discourage individuals from getting tested (Hirono, 2018).

Progress in achieving higher rates of early diagnosis have remained a challenge across Scotland. Among HIV positive individuals, there is evidence that some people are diagnosed at a late stage of HIV infection. In certain cases, this can be several years after becoming infected with the virus and when they may have progressed to advanced HIV disease or

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AIDS. Often, individuals with HIV infection visit health care services for years before receiving a diagnosis but are never tested for HIV. In 2019, 49 of 167 (29%) first ever HIV diagnoses in Scotland were diagnosed at a late stage<sup>a</sup> of infection and half of these were at a very late stage<sup>b</sup> where diagnosis presented with advanced HIV disease (Health Protection Scotland, 2020). HIV testing is critical in reducing HIV transmissions as it decreases the number of PLHIV who are unaware of their status, where timely access to treatment can help achieve and sustain viral suppression and dramatically increases a person's quality of life and overall health outcomes.

Whilst the availability of condoms, and post- and pre-exposure prophylaxis (PEP and PrEP, respectively) is important to mitigate the risk of HIV infection, expanding and scaling up HIV testing services is critical to reduce the levels of undiagnosed HIV and to meet Scotland's renewed calls of reaching zero new HIV transmissions by 2030. HIV testing services need to be focused on reaching populations and settings where the HIV burden is greatest in order to achieve greater impact. New HIV testing approaches, like self-testing, can help identify and link greater numbers of PLHIV to early treatment and care, maximizing HIV prevention potential and treatment effectiveness.

## Background

Widespread availability of HIV self-testing has the potential to overcome disparities in access to and uptake of HIV testing, particularly among key populations. Studies have shown that access to HIV self-testing can significantly remove certain barriers that reinforce negative health seeking behaviours among at-risk populations. Whilst HIV self-testing does not provide an HIV diagnosis and all HIV positive reactive results from self-testing must be confirmed<sup>c</sup>, HIV self-testing may stimulate demand for and increase uptake of HIV testing among key population groups (Figueroa, Johnson, Verster, & Baggaley, 2015).

A Scottish questionnaire survey (Flowers, et al., 2017) among 887 men who have sex with men (MSM) within the commercial gay scene in Edinburgh, Glasgow, and Dundee shows approximately half of those surveyed were aware of the availability of HIV self-testing. When informed of the availability, 89% of respondents indicated a willingness to use a self-test and, of those, 77% would use a self-test if a condom burst or after having unprotected sex. 75% would rather use a self-test kit instead of presenting at a clinic, 65% would self-test before having sex with a new partner, and 60% would use a self-test kit instead of a home-sampling kit. Notably, 80% reported they would likely use self-testing kits if they were freely available through the NHS.

According to a UK study (Witzel, Rodger, Burns, Rhodes, & Weatherburn, 2016), self-tests were shown to increase frequency of testing among 47 MSM accessing HIV self-test. Participants valued that the self-test kits were convenient and confidential. Accessing the testing kits through the post was favoured over accessing kits in health care settings. However, a range of options was reported as necessary to ensure access and, in some cases, individuals indicated a fear of needles or blood meant they would not use an HIV self-testing kit unless a saliva option was available. Additionally, some of the study participants raised concerns about linking people with reactive results to care and treatment and the impact this could have on disease progression and the potential for onward transmission.

<sup>&</sup>lt;sup>a</sup> Late HIV diagnosis is defined by a CD4 count of <350 cells per cubic millimetre recorded within 90 days of HIV diagnosis. <sup>b</sup> Very late HIV diagnosis is defined by a CD4 count of <200 cells per cubic millimetre recorded within 90 days of HIV diagnosis.

<sup>&</sup>lt;sup>c</sup> An HIV self-test does not provide an HIV diagnosis. Non-reactive (negative) self-test results are considered negative, but all reactive (positive) results need to be confirmed by laboratory testing. Whilst a reactive result shows that the test has reacted to a substance in blood, this does not necessarily mean a positive HIV result. Like any screening test, a reactive result must be confirmed with a follow-up test.

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In a UK national pilot (Brady M., et al., 2017), 4975 HIV self-test kits were delivered, with 62% (n=3021) informing authors of their results. 98% kits were ordered by men and 99% of those identified as MSM; 76% identified as white British; 3% as black African. 91% were delivered to urban areas. Of those who reported their results, 19% had never had an HIV test before. 28 reported a reactive result; one reported a false-positive and three already knew their HIV positive status. Of the remaining 24 who reported a reactive result, 22 (92%) were linked to care and treatment.

## **HIV Self Test Scotland**

In light of the advantages of HIV testing and a renewed and reinvigorated policy priority in achieving zero new HIV transmissions by 2030, HIV Scotland received a small amount of funding from Gilead Sciences<sup>™</sup> to pilot an HIV self-testing programme for Scotland. The initial £6000 funding covered 300 tests (at £15 per test kit) and the development of an online platform for ordering self-test kits and reporting results. To ensure the success of the project, HIV Scotland partnered with Waverley Care to develop an HIV self-testing pilot, offering postal access to fast and reliable HIV self-test kits. The partnership pilot is known as <u>HIV Self</u> <u>Test Scotland</u>. HIV Scotland take responsibility for processing and fulfilling orders, while Waverley Care deliver the live chat and support function of the pilot.

The self-test kits are offered for free, although those ordering a kit are given the option to make a £15 donation if they wish to do so BioSure<sup>™</sup> provides the test kits and ensures delivery to the recipient for £10.95 per test kit. Most orders are delivered within seven working days by UK Royal Mail<sup>™</sup>. As the demand for HIV self-test grew, a further £6,990 was funded by ViiV Healthcare (466 tests at £15 per test kit). Additionally, nine NHS health boards<sup>d</sup> purchased a total of 2,417 HIV self-test kits for their respective board, representing £36,255 (£15 per test kit).

NHS Health Board	No. of HIV Self Test Kits Purchased	No. of HIV Self Test Kits Used	Total Cost of Purchased Kits
NHS Ayrshire & Arran	0	60	£0
NHS Borders	200	36	£3,000
NHS Dumfries & Galloway	0	28	£0
NHS Fife	200	164	£3,000
NHS Forth Valley	87	76	£1,305
NHS Grampian	300	198	£4,500
NHS Greater Glasgow & Clyde	0	742	£0
NHS Highland	200	161	£3,000
NHS Lanarkshire	200	117	£3,000
NHS Lothians	1000	1109	£15,000
NHS Orkney	0	3	£0
NHS Shetland	0	4	£0
NHS Tayside	200	102	£3,000
NHS Western Isles	30	4	£450

 Table 0.1: HIV Self Test Scotland – Quantity and cost of purchased HIV self-test kits by NHS

 health board.

The pilot programme comes at a critical time. Despite HIV testing being an indispensable tool to link people to HIV prevention, treatment, care and support and to achieve higher rates of early diagnosis, COVID-19 continues to limit the availability and scope of health and sexual health services in Scotland. HIV Self Test Scotland bridges this gap by providing a free and

<sup>&</sup>lt;sup>d</sup> NHS Borders, NHS Fife, NHS Forth Valley, NHS Grampian, NHS Highland, NHS Lanarkshire, NHS Lothian, NHS Tayside and NHS Western Isles purchased 2417 HIV self-test kits between 15 April and 29 September 2020.

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confidential HIV test delivered to people's homes. The strategic focus of the HIV self-testing pilot in Scotland is critical in reaching those most at risk and diagnosing people as early as possible in order to link people to treatment, care and support.

## Methodology

An online research survey (see Appendix C) was carried out to evaluate HIV Self Test Scotland. To the best of our knowledge, this is the most in-depth and comprehensive research conducted in Scotland on the experiences of HIV self-test users, the acceptability of an HIV Self Test service in Scotland, and to evaluate the service in-line with user expectations. The survey design was based on the Self-Testing Public Health Intervention (SELPHI) study (Witzel, et al., 2019) with advice and support from the SELPHI team.

## Results

#### **Top-line Data**

Top-line data are separated between total orders and results. Orders data are presented by a breakdown of total number of orders and health board. Results data are presented by total number of individuals submitting results and results by health board. Demographic data is limited to those who provided this information. Top-line data provided is for period 15 April to 29 September 2020.

#### Orders

Between 15 April and 29 September 2020, a total of 2,805 individuals ordered 2,811 HIV self-test kits through HIV Self Test Scotland. This includes 155 test kits which were delivered to individuals who donated  $\pounds$ 20 (total of  $\pounds$ 3,100).

NHS Health Board	Total Orders
NHS Ayrshire & Arran	60
NHS Borders	36
NHS Dumfries & Galloway	28
NHS Fife	164
NHS Forth Valley	76
NHS Grampian	198
NHS Greater Glasgow & Clyde	742
NHS Highland	161
NHS Lanarkshire	117
NHS Lothian	1109
NHS Orkney	3
NHS Shetland	4
NHS Tayside	102
NHS Western Isles	4
Orders outwith of Scotland	1

 Table 1.1: HIV Self Test Scotland – Total Orders as of 29 September 2020.

#### Results

1,124 of the 2,805 (40%) individuals submitted their results online; eight (0.71%) individuals reported a positive reactive result. It is important to note that not everyone who has ordered and performed an HIV self-test through HIV Self Test Scotland have reported their results or provided demographic data. Because of this, there may be an underreporting of reactive results. Of the eight, seven individuals identified as gay men and one as bisexual. Six reported being between the ages 25 and 23, one between 45 and 54 and one between 55 and 64. Four identified as white, white Scottish or white British; two as another white ethnic

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group, one as Asian, Asian Scottish or Asian British; and one did not disclose ethnicity. Seven reported not having ever injected drugs; one did not disclose having ever injected drugs.

Among those that showed a reactive result, six individuals were linked to treatment and care through the HIV Self Test Scotland live chat function managed by Waverley Care. In all cases, individuals were referred to their local sexual health clinic for confirmatory testing. All individuals linked to treatment and care were made aware of the availability of ongoing support from Waverley Care throughout the process.

#### **Top-line Demographic**

1,699 of the 2,805 individuals provided demographic data, of whom 76% identified as male, 21% as female and 2% as non-binary. 1% did not disclose their gender. 74% identified as White, White Scottish or White British; 7% from another white ethnic group; 4% identified as Asian, Asian Scottish or Asian British; 2% as Black, Black Scottish or Black British; 1% as Latino or Hispanic, Latino or Hispanic Scottish or Latino or Hispanic British and 1% as mixed or multiple ethnic background. 10% did not disclose ethnicity. 57% identified as a gay man, 24% as heterosexual/straight, 13% as bisexual and 1% identified in another way. 4% did not disclose their sexual orientation.

		Is your gender the same as the sex you were assigned at birth?			
Gender	Total	Yes	No	Did not disclose	Prefer not to say
Male	1291	1272	7	10	2
Female	359	347	6	5	1
Non-binary	26	6	16	0	4
Did not disclose	18	16	0	2	0
Prefer not to say	5	3	0	1	1

Table 1.2: HIV Self Test Scotland – Demographic Distribution by Gender

#### Table 1.3: HIV Self Test Scotland – Demographic Distribution by Ethnicity

Ethnicity	Total
Arab, Arab Scottish or Arab British	8
Asian, Asian Scottish or Asian British	66
Black, Black Scottish or Black British	41
Latino or Hispanic, Latino or Hispanic Scottish or Latino or Hispanic British	12
Mixed or Multiple ethnic groups	21
Other White ethnic group	126
White, White Scottish or White British	1253
Did not disclose	172

#### Table 1.4: HIV Self Test Scotland – Demographic Distribution by Sexual Orientation

Sexual Orientation	Total
Bisexual	221
Gay man	976
Gay woman/lesbian	7
Heterosexual/straight	404
In another way	16
Did not disclose	37
Prefer not to say	38

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 Table 1.5: HIV Self Test Scotland – Individuals having ever injected drugs in the past six months

Injected drugs in the last six months?	Total
Yes	21
No	1529
Did not disclose	149

#### **Survey Data**

HIV Self Test Scotland administered an online survey to individuals who had ordered an HIV self-test through the HIV Self Test Scotland website and who consented to take part in a survey to evaluate the service. The survey aimed to better understand the service user's expectations of a HIV Self Test programme in Scotland, to help improve HIV Self Test Scotland's processes and customer service, and to evaluate its future viability and sustainability. The survey was administered between the 6<sup>th</sup> and 23<sup>rd</sup> of August. Those who completed the survey had a chance to win an Apple Watch Series 5; the winner to be randomly selected. The survey was completely anonymous unless participants wanted a chance to win the Apple Watch or wanted HIV Self Test Scotland to contact them for advice or support with their test results.

A total of 849 individuals consented to take part in the survey; 384 (45%) responded. Survey data are separated by demographics, knowledge and history of PEP and PrEP, sexual and injecting drug history, testing behaviours, risk perception, ordering and usability, results and linkages to care, customer service and acceptability. 168 reported that they were willing to take part in a follow-up interview.

#### Survey Demographic

Of the 384 respondents, 88% identified as male (including trans male), 10% as female (including trans female) and 2% as non-binary. 65% identified as White Scottish; 12% as White British and 11% as White Other. African, African Scottish or African British; Other Asian, Asian Scottish or Asian British; White Irish and mixed or multiple ethnic groups each represented 2% of the survey respondents. Consistent with the top-line data, 78% identified as a gay man, 11% as heterosexual/straight, 10% as bisexual and 1% identified in another way. 1% did not disclose their sexual orientation. See **Appendix A** for demographic data by NHS health board.

NHS Health Board	Total
NHS Ayrshire & Arran	11
NHS Borders	7
NHS Dumfries & Galloway	5
NHS Fife	24
NHS Forth Valley	11
NHS Grampian	27
NHS Greater Glasgow & Clyde	125
NHS Highland	15
NHS Lanarkshire	11
NHS Lothian	121
NHS Shetland	*
NHS Tayside	14
NHS Western Isles	*
Prefer not to say	6
Did not disclose	*

Table 2.1: HIV Self Test Scotland Evaluation – Distribution by NHS Health Board

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 Table 2.2: HIV Self Test Scotland Evaluation – Distribution by Gender

		Is your gender the same as the sex you were assigned at birth?		
Gender	Total	Yes	No	Prefer not to say
Male (including trans male)	339	337	2	0
Female (including trans female)	37	35	2	0
In another way	1	1	0	0
Non-binary	6	1	3	2
Did not disclose	1	1	0	0

#### **Table 2.3**: HIV Self Test Scotland Evaluation – Distribution by Age

Age	Total
Under 18	3
Between 18 – 24	59
Between 25-34	164
Between 35-44	90
Between 45-54	45
Between 55-64	19
Over 65	4

 Table 2.4: HIV Self Test Scotland Evaluation – Distribution by Sexual Orientation

Sexual Orientation	Total
Bisexual	38
Gay man	298
Heterosexual/straight	43
In another way	3
Prefer not to say	2

#### Table 2.5: HIV Self Test Scotland Evaluation – Distribution by Ethnicity

Ethnicity	Total
African, African Scottish or African British	6
Any mixed or multiple ethnic groups	8
Arab, Arab Scottish or Arab British	1
Chinese, Chinese Scottish or Chinese British	3
Did not disclose	1
Gypsy / Traveller	2
Indian, Indian Scottish or Indian British	2
Latino or Hispanic, Latino or Hispanic Scottish or Latino or Hispanic British	2
Other Asian, Asian Scottish or Asian British	6
Other Caribbean or Black	2
Other White British	47
Pakistani, Pakistani Scottish or Pakistani British	3
White Irish	6
White Other	43
White Polish	4
White Scottish	248

#### Table 2.6: HIV Self Test Scotland Evaluation – Individuals having ever injected drugs.

Have you ever injected drugs?	Total
Yes	14
No	370

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**Table 2.7**: HIV Self Test Scotland Evaluation – Individuals having ever exchanged sex for money or other goods.

Have you ever exchanged sex for money or other goods?	Total
Yes	37
No	347

#### **PrEP and PEP**

Pre-Exposure Prophylaxis (PrEP) and Post Exposure Prophylaxis (PEP) are both HIV preventative measures that can be taken to decrease the risk of acquiring HIV. PEP involves taking antiretroviral drugs after being exposed to HIV, whereas PrEP involves a daily or event-based dose of antiretroviral drugs to reduce the risk of HIV transmissions from subsequent exposures. Both PEP and PrEP have shown to be an effective way in preventing the acquisition of HIV, where a large-scale PrEP study has reported that HIV transmission is effectively zero PrEP is taken as prescribed (Rodger, et al., 2019).

The survey asked respondents about their knowledge and use of PrEP. 86% of all survey respondents reported that they had heard of PrEP before. Men (91%) reported higher awareness, followed by non-binary people (83%) and then women (43%). 94% of gay male and 87% of bisexual respondents reported having heard of PrEP, whereas only 35% of heterosexual/straight respondents did. Of the respondents that had heard of PrEP before, 28% had taken PrEP before and 16% were currently on PrEP. Respondents who reported currently taking PrEP received their PrEP via a sexual health clinic (87%) or sourced through an online pharmacy (13%). 58% took PrEP every day and 42% when they needed to (event-based/event-driven dosing<sup>e</sup>).

		Have y	ou heard of	PrEP before?
Gender	Total	Yes	No	Did not disclose
Male (including trans male)	339	308	30	1
Female (including trans female)	37	16	21	0
Non-binary	6	5	1	0
In another way	1	1	0	0
Did not disclose	1	1	0	0

 Table 3.1: HIV Self Test Scotland Evaluation – PrEP Awareness by Gender

 Table 3.2: HIV Self Test Scotland Evaluation – PrEP Awareness by Sexual Orientation

		Have	you he	ard of PrEP before?
Sexual Orientation	Total	Yes	No	Did not disclose
Bisexual	38	33	5	0
Gay man	298	##	17	1
Heterosexual/straight	43	15	28	0
In another way	3	3	0	0
Prefer not to say	2	0	2	0

We also asked respondents about their knowledge and use of PEP. 74% of all survey respondents reported that they had heard of PEP before. Non-binary individuals (83%) reported higher awareness, followed by men (78%) and then women (32%). 81% of gay male and 76% of bisexual respondents reported having heard of PEP, whereas only 26% of heterosexual/straight respondents did. Of the respondents that have heard of PEP before, 15% had taken PEP before. Of those, 1% took PEP within the last four weeks; 16% within

<sup>&</sup>lt;sup>e</sup> Event-driven PrEP involves taking a double dose of PrEP (two pills) between two and 24 hours before sex is anticipated, and then, if sex occurs, one pill 24 hours after the double dose and another 24 hours later. If sex occurs several days in a row, one pill is taken each day, until 48 hours after the last event.

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the last two months; 16% within the last 12 months; 27% within the last two years; 27% within the last five years and 18% over five years ago.

		Have you heard of PEP before?		
Gender	Total	Yes	No	Did not disclose
Male (including trans male)	339	265	73	1
Female (including trans female)	37	12	25	0
Non-binary	6	5	1	0
In another way	1	1	0	0
Did not disclose	1	1	0	0

Table 3.3: HIV Self Test Scotland Evaluation – PEP Awareness by Gender

 Table 3.3: HIV Self Test Scotland Evaluation – PEP Awareness by Sexual Orientation

		Have y	PEP before?	
Sexual Orientation	Total	Yes	No	Did not disclose
Bisexual	38	29	9	0
Gay man	298	241	56	1
Heterosexual/straight	43	11	32	0
In another way	3	2	1	0
Prefer not to say	2	1	1	0

### **Sexual and Injecting Drug History**

We asked respondents to provide details about their sexual and injecting drug history in order to better understand the context of risk behaviours. 92% of all survey respondents reported having had sex with cis<sup>f</sup> men in the past 12 months, followed by cis women (8%), trans men (2%) and trans women (1%). Respondents reported having had penetrative anal sex (74%), given (88%) and received (85%) oral sex, receptive anal sex (57%), penetrative vaginal/front hole sex (13%) and receptive vaginal/front hole sex (6%).

Of the respondents having ever injected drugs (n=14, see **Table 2.6**), 50% reported having injected methamphetamine (crystal meth), 29% heroin, 29% cocaine, 29% mephedrone, 14% ketamine, 7% crack cocaine and 7% MDMA. 7% reported having injected drugs within the last four weeks, 7% within the last six months, 14% within the last 12 months, 29% within the last two years, 15% within the last five years and 29% over five years ago. 86% stated that they had used drugs during or to enhance sex.

Of the respondents having ever exchanged sex for money or other goods (n=37, see **Table 2.7**), 8% reported exchanging sex within the last four weeks, 3% within the last three months, 14% within the last six months, 16% within the last 12 months, 5% within the last two years, 5% within the last five years and 46% over five years ago.

#### **HIV Testing**

HIV-related stigma, low risk perception, fear of a positive diagnosis, confidentiality and, in some cases, the inability to access testing, are some of the central features that discourage individuals from seeking HIV testing services (Hirono, 2018). 27% of all respondents reported that the HIV self-test ordered from HIV Self Test Scotland was the first time they ever tested for HIV. Of those, 75% were male, 21% female, 3% non-binary and 1% did not disclose gender. Overall, three individuals reported a reactive (positive) self-test result with one individual reporting no previous HIV testing history.

<sup>&</sup>lt;sup>f</sup> Cis or cisgender describes people whose gender identity is the same as the sex they were assigned at birth.

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**Table 4.1**: HIV Self Test Scotland Evaluation – First time taking an HIV test using service by

 Gender

	Was the H	IV Self Test Scot ever take	land HIV test the first	
Gender	Total	Yes	No	Did not disclose
Male (including trans male)	339	79	258	2
Female (including trans female)	37	22	15	0
In another way, please describe	1	0	1	0
Non-binary	6	3	3	0
Did not disclose	1	1	0	0

**Table 4.2**: HIV Self Test Scotland Evaluation – First time taking an HIV test using service by

 Sexual Orientation

		Was the HIV Self Test Scotland HIV test the first ever taken			
Sexual Orientation	Total	Yes	No	Did not disclose	
Bisexual	38	14	24	0	
Gay man	298	66	230	2	
Heterosexual/straight	43	22	21	0	
In another way	3	2	1	0	
Prefer not to say	2	1	1	0	

Of the 72% that had had an HIV test before, when asked when they last took an HIV test, 11% reported within the last four weeks, 15% within the last three months, 24% within the last six months, 24% within the last 12 months, 14% within the last two years, 10% within the last five years and 3% over five years ago. Excluding the last HIV test received from HIV Self Test Scotland, 69% reported they took their last HIV test at a sexual health clinic, 13% used a self-test kit from HIV Self Test Scotland, 12% used a self-test kit from another provider, 8% from a GP, 7% used a self-sampling service<sup>9</sup>, 5% from a community testing services<sup>h</sup> and 3% from a hospital.

Table 4.3: HIV Self Test Scotland Evaluation – First time taking an HIV test using service

HIV testing location	Total
Sexual health clinic	191
I used a self-test kit from HIV Self Test Scotland	36
I used a self-test kit from another provider	34
GP	21
I used a self-sampling kit	19
Community testing service	13
Hospital	8
Another location	7

#### **STI Testing**

82% of all respondents had tested for an STI other than HIV. Of those, 88% identified as male, 9% female and 2% non-binary. 94% identified as gay men, 14% as heterosexual/straight and 12% as bisexual. 11% last tested for an STI within the last 4 weeks, 9% within the last 3 months, 21% within the last 6 months, 25% within the last 12 months, 16% within the last 2 years, 9% within the last 5 years and 9% over 5 years ago.

<sup>&</sup>lt;sup>g</sup> Self-sampling involves collecting your own sample, either of blood or of moisture from your mouth, and sending the specimen to a laboratory for analysis.

<sup>&</sup>lt;sup>h</sup> A testing service not based in an NHS or private health facility.

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		Have you ever been tested for an STI?		
Gender	Total	Yes	No	Did not disclose
Male (including trans male)	339	279	55	5
Female (including trans female)	37	30	7	0
Non-binary	6	5	0	1
In another way	1	1	0	0
Did not disclose	1	1	0	0

 Table 5.1: HIV Self Test Scotland Evaluation – Ever tested for an STI by Gender

Table 5.2: HIV Self Test Scotland Evaluation - Ever tested for an STI by Sexual Orientation

	-	Have you ever been tested for an STI?		
Sexual Orientation	Total	Yes	No	Did not disclose
Bisexual	38	29	9	0
Gay man	298	248	46	4
Heterosexual/straight	43	35	7	1
In another way	3	3	0	0
Prefer not to say	2	1	0	1

Of those who have tested for an STI other than HIV, 14% reported having been diagnosed with an STI in the last 12 months, where 58% reported having been diagnosed with chlamydia, 49% gonorrhoea, 9% syphilis, 4% herpes and 2% with non-specific urethritis. Of those, 93% identified as male, 4% female and 2 % non-binary; 89% identified as gay men, 9% as bisexual and 2% as heterosexual/straight.

**Table 5.3**: HIV Self Test Scotland Evaluation – Number of respondents reporting a diagnosis by infection

Type of diagnosis	Total
Chlamydia	26
Gonorrhoea	22
Syphilis	4
Herpes	2
Non-specific urethritis (NSU)	1
Genital warts	0
Hepatitis B	0
Hepatitis C	0
I don't know	0

Table 5.4: HIV Self Test Scotland Evaluation - STI diagnosis (excluding HIV) by Gender

		Have you been diagnosed with an STI in the last 12 months?		
Gender	Total	Yes	No	
Male (including trans male)	339	42	237	
Female (including trans female)	37	2	28	
Non-binary	6	1	4	
In another way	1	0	1	
Did not disclose	1	0	1	

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**Table 5.5**: HIV Self Test Scotland Evaluation – STI diagnosis (excluding HIV) by Sexual Orientation.

		Have you been diagnosed with an STI in the last 12 months?				
Sexual Orientation	Total	Yes	No			
Bisexual	29	4	25			
Gay man	248	40	208			
Heterosexual/straight	35	1	34			
In another way	3	0	3			
Prefer not to say	1	0	1			

#### **Risk Perception**

There is a clear link between risk awareness and HIV testing. Low risk perception transcends communities and is frequently cited as a major barrier to HIV testing uptake (Hirono, 2018). To gain a better understanding of risk awareness among our respondents, we asked why they thought they may have been at risk of contracting HIV, what made them think they were at risk of contracting HIV and why they decided to take a HIV self-test.

30% of all survey respondents reported they thought they may have been at risk of contracting HIV; 38% reported that they were not at risk and 31% were not sure. Of those that thought they were at risk, 88% identified as male, 9% female and 3% non-binary; 77% identified as gay men, 11% as bisexual and 9% as heterosexual/straight.

**Table 6.1**: HIV Self Test Scotland Evaluation – Do you think you may have been at risk of contracting HIV? by Gender.

	Do you think you may have been at risk of contracting HIV?				
Gender	Total	Yes	Not sure	No	Did not disclose
Male (including trans male)	339	100	98	136	5
Female (including trans female)	37	10	20	7	0
In another way	1	1	0	0	0
Non-binary	6	3	1	1	1
Did not disclose	1	0	0	1	0

**Table 6.2**: HIV Self Test Scotland Evaluation – Do you think you may have been at risk of contracting HIV? by Sexual Orientation.

		Do you think you may have been at risk of contracting HIV?				
Sexual Orientation	Total	Yes	Not sure	No	Did not disclose	
Bisexual	38	12	16	10	0	
Gay man	298	88	81	126	3	
Heterosexual/straight	43	10	22	9	2	
In another way	3	3	0	0	0	
Prefer not to say	2	1	0	0	1	

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#### **Table 6.3**: HIV Self Test Scotland Evaluation – Risk perception.

Why do you think you may have been at risk of contracting HIV?	Total
Unprotected sex	136
Unknown HIV status of sexual partner(s)	38
Known HIV status of sexual partner(s)	12
I belong to a high-risk demographic	8
Ineffective prevention (i.e. condom broke)	8
I have/had multiple sexual partners	6
Did not use PrEP	2
Not at risk, just want to know my status	2
Exposure to blood of unknown HIV status	1
Injecting drug use	1
Showing possible symptoms	1
Other	7
Prefer not to say	1

76% of all respondents stated that the reason they decided to order an HIV self-test kit was for peace of mind, followed by wanting to know their status (71%), the ability to test from home 48%), convenience (45%) and because it was a free service (42%) (see Table 6.4 below for all listed reasons why respondents ordered an HIV self-test through HIV Self Test Scotland).

 Table 6.4: HIV Self Test Scotland Evaluation – Decision for ordering an HIV Self-Test.

What made you decide to order an HIV self-test kit?	Total
Peace of mind	291
I want to know my status	272
Ability to test from home	184
Convenience	172
It's a free service	160
Routine test	146
Privacy	140
It's the only testing service I could access	109
New relationship/sexual partner	58
Another reason, please describe	19
Advised to get tested	13
Prefer not to say	2
Travel purposes (i.e. condition for a travel visa)	1

#### Ordering the Biosure<sup>™</sup> HIV Self-Test

To evaluate user satisfaction with the service, we asked respondents whether they experienced any problems when ordering the BioSure <sup>™</sup> HIV self-test through the HIV Self Test Scotland website and whether they encountered any issues when using the HIV self-test.

When asked how far they agreed that they were "able to order the HIV self-test kit without any problems," 92% of all survey respondents strongly agreed and 3% agreed; 5% did not disclose.

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**Table 7.1**: HIV Self Test Scotland Evaluation – Able to order the HIV self-test kit without any problems.

I was able to order the HIV self-test kit without any problems		
Strongly agree	352	
Agree	21	
Did not disclose/skipped question	11	

**Table 7.2**: HIV Self Test Scotland Evaluation – Able to order the HIV self-test kit without any problems by Gender

		Able to order the HIV self-test kit without any problems?			
Gender	Total	Strongly agree	Agree	Did not disclose / skipped question	
Female (including trans female)	37	32	2	3	
Male (including trans male)	339	313	19	7	
Non-binary	6	5	0	1	
In another way	1	1	0	0	
Did not disclose	1	1	0	0	

**Table 7.3**: HIV Self Test Scotland Evaluation – Able to order the HIV self-test kit without any problems by Sexual Orientation

		Able to order the HIV self-test kit without any problems?					
Sexual Orientation	Total	Strongly agree Agree		Did not disclose / skipped question			
Gay man	298	280	12	6			
Heterosexual/straight	43	37	3	3			
Bisexual	38	31	6	1			
In another way	3	3	0	0			
Prefer not to say	2	1	0	1			

We also asked all survey respondents on how much they agreed that they "received the HIV self-test kits without any problems;" 93% strong agreed; 3% agreed, 1% neither agreed nor disagreed.

**Table 7.4**: HIV Self Test Scotland Evaluation – Receiving an HIV self-test kit without any problems.

I received the HIV self-test kit without any problems	Total
Strongly disagree	1
Agree	12
Neither agree or disagree	2
Strongly agree	357
Did not disclose/skipped question	12

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**Table 7.5**: HIV Self Test Scotland Evaluation – Able to receive the HIV self-test kit without any problems by Gender

		Able to receive the HIV self-test kit without any problems?					
Gender	Total	Strongly agree	Agree	Neither agree or disagree	Strongly disagree	Did not disclose / skipped question	
Female (including trans female)	37	34	0	0	0	3	
Male (including trans male)	339	316	12	2	1	8	
Non-binary	6	5	0	0	0	1	
In another way	1	1	0	0	0	0	
Did not disclose	1	1	0	0	0	0	

**Table 7.6**: HIV Self Test Scotland Evaluation – Able to receive the HIV self-test kit without any problems by Sexual Orientation

		Able to receive the HIV self-test kit without any problems?						
Sexual Orientation	Total	Strongly agree	Agree	Neither agree or disagree	Strongly disagree	Did not disclose / skipped question		
Gay man	298	281	8	1	1	7		
Heterosexual/straight	43	37	2	1	0	3		
Bisexual	38	35	2	0	0	1		
In another way	3	3	0	0	0	0		
Prefer not to say	2	1	0	0	0	1		

### Using the Biosure<sup>™</sup> HIV Self-Test

Among all survey respondents, 96.6% reported that they used the HIV self-test kit themselves, 0.8% said 'no' and 2.6% did not disclose whether this was the case. Of the three respondents who reported they did not take the test themselves, two stated that they had not taken the test yet and one hadn't yet received his self-test kit.

**Table 8.1**: HIV Self Test Scotland Evaluation – HIV Self-Test Usability, did you use the self-test kit yourself?

Did you use the kit to test yourself?	Total
Yes	371
No	3
Did not disclose/skipped question	10

English instructions (*see* **Appendix D**) on how to use the Biosure<sup>™</sup> self-test kit are included in the delivery of the self-test kit. Users must draw a blood sample using a capillary lancet, collect the sample in a test stick, push the test stick into a buffer pot, then wait 15 minutes before interpreting the result using included instructions. The user can visit the HIV Self-Test Scotland website for instructions in French, German, Italian, Brazilian Portuguese and Chinese and for further guidance, available through a Biosure<sup>™</sup> HIV self-test video and a 'frequently asked questions' section. Users are also able to contact HIV Self Test Scotland for further instructions or questions using the website live chat function.

We asked respondents what instructions they used to take the HIV self-test kit. A significant majority of all survey respondents used the paper instructions enclosed in the test (90%) and

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over a quarter (27%) using the Biosure<sup>™</sup> HIV self-test video as guidance. 80% of all respondents strongly agreed that the instructions were easy to use, followed by 14% who stated they agreed (94%, collectively). Two respondents stated that they 'neither disagreed or agreed' or 'disagreed', respectively.

85% strongly agreed that performing the test was simple, followed by 14% who agreed. Two respondents stated they 'neither agreed or disagree' and one 'disagreed' that performing the test was simple. A significant majority of respondents reported a positive experience with the Biosure<sup>™</sup> self-test kit, where 89% strongly agreed and 10% agreed that their overall experience was good.

**Table 8.2**: HIV Self Test Scotland Evaluation – HIV Self-Test Usability, what instructions did you use?

What instructions did you use	Total
Biosure™ HIV self-test video	103
The paper instructions enclosed in the test	346
Guidance on HIV Self Test Scotland website	33
I didn't use instructions	3
Did not disclose/skipped question	16

Table 8.3: HIV Self Test Scotland Evaluation – HIV Self-Test Usability, overall experiences.

	Strongly Disagree	Disagree	Neither agree or disagree	Agreed	Strongly agreed	Did not disclos e
Were the instructions easy to use?	0	1	1	55	308	19
Was performing the test simple?	0	1	2	50	315	16
My overall experience with the self-test kit was good.	1	1	2	36	327	17

### **Results & Linkage into Clinical Services**

93% of all survey respondents reported a negative (non-reactive) test result and 1% reported a positive (reactive) result. Four individuals stated that their Biosure<sup>™</sup> self-test did not work. Some of the feedback reported on why the test did not work: *"It didn't show the lines." "Blood wouldn't go up the tube although [it] had plenty of blood."* 

Table 8.1: HIV Self Test Scotland Evaluation – Biosure™ HIV Self-Test Results

What was the results of your HIV self-test?	Total
Positive (reactive result)	3
Negative (non-reactive result)	359
The test did not work	4
Did not disclose/skipped question	18

When asked if respondents had been to a clinic or doctor to have their results confirmed, two stated that they had not, two had with positive confirmation test results and one had with a negative confirmation test. Of the two who had not had their results confirmed, they declined requests from HIV Self Test Scotland to contact them to discuss their results or help them access a confirmation test. The two respondents who have had their positive confirmation test are now under the care of an HIV clinician and accessing treatment.

### User Experience with HIV Self Test Scotland

HIV Self Test Scotland provided assistance and advice to those who sought it to ensure an overall positive experience when ordering and using the Biosure<sup>™</sup> self-test kit. 2% (n=9) of

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all survey respondents reported having contacted HIV Self Test Scotland with any questions or concerns regarding the service or self-test kit. Of those, the most often asked question was about the delivery processes (n=8, 75%), such as when they could expect delivery or questions about the packaging of the self-test kit. Over half (n=9, 56%) of all enquiries were asked through HIV Self Test Scotland's online contact form.

Overall experience of contacting HIV Self Test Scotland has been very positive, with all of those who contacted HIV Self Test Scotland reporting that they 'strongly agree' or 'agree' that they were able to get in touch quickly and were provided with the help needed.

#### Table 9.1: HIV Self Test Scotland Evaluation – Contacting HIV Self Test Scotland.

Did you contact HIV Self Test Scotland with any questions or concerns?	Total
Yes	9
No	358
Did not disclose/skipped question	17

 Table 9.2: HIV Self Test Scotland Evaluation – Reasons for contacting HIV Self Test

 Scotland.

Why did you get in contact with HIV self-test Scotland?	Total
To ask a question about the delivery process (E.g. Packaging/delivery	
timescales)	6
To ask about a delayed order	1
To report that a self-test had not worked	1
To discuss a negative result	1
To ask about the effectiveness of self-testing or the window period	0
To ask for help with carrying out the self-test	0
To ask for help with interpreting the self-test result	0
To discuss a positive result	0

Table 9.3: HIV Self Test Scotland Evaluation – Method of contacting HIV Self Test Scotland.

How did you contact HIV self-test Scotland?	Total
Website contact form	5
Live chat function	3
Telephoning Waverley Care	1
Telephoning HIV Scotland	1

 Table 9.3: HIV Self Test Scotland Evaluation – Overall experience of contacting HIV Self

 Test Scotland.

	Strongly Disagree	Disagree	Neither agree or disagree	Agreed	Strongly agreed
I was able to get in touch with HIV Self Test Scotland quickly	0	0	0	3	6
HIV Self Test Scotland provided me with the help or advice I needed	0	0	0	2	7

#### Acceptability

HIV Self Test Scotland is a pilot project designed to measure the acceptability of and demand for HIV self-tests in Scotland, in order to assess further intervention developments and scaleup. There are limited studies on the acceptability of HIV self-tests on actual users; most studies examine the acceptability of potential users. This evaluation aims to establish a benchmark on actual user acceptability, demand for HIV self-testing and future sustainability of HIV Self Test Scotland.

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Overall, 95% of all survey respondents reported that they would recommend HIV Self Test Scotland to other people; 1% were not sure and 4% did not disclose. When asked whether they would order an HIV self-test from HIV Self Test Scotland again, 93% of all survey respondents reported that they would, where 83% would prefer using a blood sample and 47% using a saliva sample.

 Table 9.1: HIV Self Test Scotland Evaluation – Would you recommend HIV Self Test

 Scotland?

Would you recommend HIV Self Test Scotland to other people?	Total
Yes	365
No	0
Not sure	2
Did not disclose/skipped question	17

 Table 9.2: HIV Self Test Scotland Evaluation – Would you order another HIV Self-Test?

Would you order an HIV self-test from HIV Self Test Scotland again?	Total
Yes	357
No	0
I don't know	7
Did not disclose/skipped question	20

Table 9.3: HIV Self Test Scotland Evaluation – Preference for type of HIV Self-Test

How would you prefer to self-test in the future?	Total
Using a blood sample	320
Using a saliva sample	182
Neither blood nor saliva	6
Did not disclose/skipped question	20

We also asked respondents how much they were willing to pay for an HIV self-test kit. 29% were willing to pay £10, followed by £5 (22%) and the cost of postage (16%). 13% stated they would not use the service if they had to pay.

**Table 9.4**: HIV Self Test Scotland Evaluation – Willingness to pay for an HIV self-test by amount.

How much would you be willing to pay for an HIV self-test kit?	Total
Postage costs	61
£5	84
£10	112
£15	29
£20	29
I wouldn't use the service if I had to pay	50
Did not disclose/skipped question	19

Whilst there was a wide range of reported acceptable methods of receiving HIV self-test kits, the majority of survey respondents (94%) wanted to receive their self-test kits through the post from an online order. 56% stated they would be happy picking up their self-test kits at pharmacy, 51% from a sexual health clinic and 40% from a click-and-collect location.

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Table 9.5: HIV Self Test Scotland Evaluation – Preference of receiving an HIV self-test				
How would you like to be able to receive self-test kits?	Total			
Postal delivery from online order	361			
Pick up from a pharmacy	214			
Pick up from a sexual health clinic	195			
Click-and-collect (order online and collect from a nearby location)	154			
From vending machines	127			
Pick up from a community organisation	112			
From outreach workers in community settings	99			
From sexual partners	55			
Did not disclose/skipped question	19			

Nearly half of all survey respondents (46%) stated that they did would not need any additional support using an HIV self-test beyond what was already provided by attending a sexual health clinic. However, some respondents reported the need for a dedicated live chat (34%), dedicated contact number (26%), video or online counselling (25%) or face-to-face advice from a health advisor or outreach working (20%).

Table 9.6: HIV Self Test Scotland Evaluation – Support preference when using HIV self-test.

What kind of support would you want when using HIV self-testing?	Total
No support needed beyond that available already by attending a sexual health clinic	175
Dedicated live chat	130
Dedicated phone line	98
Video / online counselling	95
Face-to-face advice (from a health advisor or outreach worker, for example)	78
Did not disclose/skipped question	23

## Conclusion

Despite Scotland's successes in achieving global targets, there remains a need to realign efforts in response to the changing HIV landscape. Notably, COVID-19 has had a significant impact on the availability of sexual health services across Scotland, including HIV testing services. Safeguarding measures implemented by the Scottish Government during the pandemic, such as quarantine, social distancing and regional containment, have reduced people's access to routine HIV testing whilst health services limit their services in order to decongest an overburdened health system. Therefore, to ensure the continuation of HIV testing services for all communities across Scotland, HIV Scotland and Waverley Care established HIV Self Test Scotland to ensure that anyone who needs an HIV test can freely access one, and to maintain a strong focus on HIV testing among priority populations in order to achieve zero new HIV transmissions by 2030.

It is clear that access to testing services is central to achieving a meaningful reduction of HIV prevalence rates. The changing landscape, coupled with shifting contributions of risk exposures remain a public health concern in Scotland, particularly within priority populations. Gay and bisexual men and men who have sex with men; people who inject drugs; transgender; and Black, Asian and minority ethnic communities; among others, continue to bear a disproportionate burden of HIV. To address the health disparity, a diversified and innovative approach to HIV testing delivery that reaches all communities across Scotland is needed to close the test gap experienced by many at-risk groups (Hirono, 2018). Given this, HIV self-testing is increasingly sought after and offered globally, yet there is limited information about the test features that will be required for an HIV self-test to be easy to use and acceptable to users. In the UK, HIV Self-Testing has shown to illicit more frequent testing, thus linking individuals to treatment and care and potentially reducing the onward transmission of HIV (Witzel, et al., 2019).

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Overall, our evaluation demonstrates that there is a high demand for HIV self-testing across Scotland and among key population groups, including gay and bisexual and men who have sex with men; people who inject drugs, heterosexual people, non-binary individuals and people who live in remote or rural settings (see **Appendix B**). Between 15 April and 29 October, 2,805 individuals ordered 2,811 HIV self-test through HIV Self Test Scotland, representing approximately 400 tests being performed per month. Whilst NHS Lothian (40%) and NHS Greater Glasgow and Clyde (26%) represent the bulk of tests being ordered, there is clear evidence that HIV Self Test Scotland is far-reaching across all health boards in Scotland. Our evaluation also suggests that the free provision of HIV self-testing plays a role in overcoming barriers to frequent HIV testing, and that online ordering for postal delivery is a feasible and acceptable means of delivery.

Overall experience throughout the entire process of ordering a Biosure<sup>™</sup> HIV Self-Test through HIV Self Test Scotland website was very positive, with the vast majority of respondents reporting having had no issues; some feeding back that the whole experience was easy, convenient and discreet. Based on the survey feedback, it was clear that many thought the service provided by HIV Self Test Scotland is essential, especially for many who experience barriers in accessing sexual health services. Further, usability of the Biosure<sup>™</sup> HIV Self-Test has also been very positive, with only one respondent citing having had difficulties in reading the enclosed instructions and one citing difficulty performing the test. The convenience and private nature of HIV self-testing through postal delivery is reportedly beneficial to many where individuals can get tested and know their HIV status within minutes.

To ensure that Scotland continues to sustain lower rates of HIV, we need to prioritise that all people living with HIV are linked to quality prevention, treatment and care and support services. Frequent HIV testing among key population groups is critical to reduce the levels of undiagnosed individuals and initiate treatment and care, and to stem the onwards transmission of HIV. To that end, HIV Self Test Scotland can fill an important 'testing' gap in this regard, especially for those population groups that are harder to reach. From our research and substantiated by current literature (Stevens, Vrana, Dlin, & Korte, 2018; Rodger, et al., 2020; Witzel, Rodger, Burns, Rhodes, & Weatherburn, 2016; Brady, et al., 2017; Krause, Subklew-Sehume, Kenyon, & Colebunders, 2013), it is clear that HIV self-testing is highly acceptable approach among key populations and is a key component of delivering a differentiated approach to reaching zero new HIV transmissions by 2030.

## **Next steps**

Both UNAIDS and the WHO recommend the scale up of HIV self-testing as an approach to reach and exceed global HIV targets (World Health Organization, 2019; UNAIDS, 2017), citing that HIV self-testing is a safe, accurate and effective way to reach people who may not test otherwise, including people from key populations and those who cannot or prefer not to access sexual health or traditional healthcare services.

There is still much to do in order to meet zero new HIV transmissions by 2030. Despite having reached and exceeded UNAIDS 90-90-90 international HIV targets, Scotland must remain focused and not succumb to complacency and lose momentum. Political leadership and commitment is critical by investing in the future of its citizens' health and wellbeing.

To do so, we must increase the capacity, breadth and scope of HIV testing across Scotland – it is clear that we can, as evidenced by this report, by expanding and investing in HIV self-testing. HIV Testing in Scotland Report (HIV Scotland, 2018) and the HIV Instant Result Self-Testing in Scotland (HIV Scotland, 2014) report provide a great starting point.

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## Limitations

Whilst our evaluation survey aimed to be representative, the degree to which the survey is representative is largely influenced by those who have consented to participate in the survey. The majority of our participants reported negative results. Thus, the data pertaining to those with positive results cannot be considered representative of the experiences of others.

Whilst the anonymous survey collected non-identifying personal information<sup>i</sup>, the survey potentially does not include those with the greatest concerns surrounding disclosures of sensitive information, arguably those that have a heightened need for HIV self-testing.

<sup>&</sup>lt;sup>i</sup> The survey was completely anonymous unless participants wanted a chance to win the Apple Watch or wanted HIV Self-Test Scotland to contact them for advice or support with their test results, upon which we asked for contact details.

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## Appendix A: Tables: Demographic by NHS health board

NHS Health Board	Male (including trans male)	Female (including trans female)	In another way	Non-binary	Did not disclose
NHS Ayrshire & Arran	8	2	1	0	0
NHS Borders	7	0	0	0	0
NHS Dumfries & Galloway	4	1	0	0	0
NHS Fife	24	0	0	0	0
NHS Forth Valley	11	0	0	0	0
NHS Grampian	24	3	0	0	0
NHS Greater Glasgow & Clyde	112	9	0	3	1
NHS Highland	10	4	0	1	0
NHS Lanarkshire	11	0	0	0	0
NHS Lothian	104	15	0	2	0
NHS Shetland	2	0	0	0	0
NHS Tayside	13	1	0	0	0
NHS Western Isles	1	0	0	0	0
Prefer not to say	4	2	0	0	0
Did not disclose	4	0	0	0	0

Table 10.1: HIV Self Test Scotland Evaluation – Gender by Health Board

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#### Table 10.2: HIV Self Test Scotland Evaluation – Sexual Orientation by Health Board

NHS Health Board	Bisexual	Gay man	Heterosexual / straight	In another way	Prefer not to say
NHS Ayrshire & Arran	1	8	2	0	0
NHS Borders	0	6	1	0	0
NHS Dumfries & Galloway	0	4	1	0	0
NHS Fife	3	20	1	0	0
NHS Forth Valley	0	11	0	0	0
NHS Grampian	4	20	3	0	0
NHS Greater Glasgow & Clyde	9	104	10	1	1
NHS Highland	3	8	2	1	1
NHS Lanarkshire	2	9	0	0	0
NHS Lothian	11	94	15	1	0
NHS Shetland	0	0	2	0	0
NHS Tayside	2	8	4	0	0
NHS Western Isles	1	0	0	0	0
Prefer not to say	0	4	2	0	0
Did not disclose	2	2	0	0	0

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Table 10.3: HIV Self Test Scotland Evaluation – Ethnicity by Health Board

NHS Health Board	Ayrshire & Arran	Borders	Dumfries &	Fife	Forth Valley	Grampian	Greater Glasgow	Highland	Lanarkshire	Lothian	Shetland	Tayside	Western Isles	Prefer not to say	Did not disclose
African, African Scottish or African British	0	0	0	0	0	1	3	0	0	0	1	1	0	0	0
Any mixed or multiple ethnic groups	0	0	0	1	0	1	2	0	0	4	0	0	0	0	0
Arab, Arab Scottish or Arab British	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Chinese, Chinese Scottish or Chinese British	0	0	0	1	0	0	1	0	0	1	0	0	0	0	0
Did not disclose	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Gypsy / Traveller	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0
Indian, Indian Scottish or Indian British	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0
Latino or Hispanic, Latino or Hispanic Scottish or Latino or Hispanic British	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0
Other Asian, Asian Scottish or Asian British	1	0	0	0	0	0	3	0	0	2	0	0	0	0	0
Other Caribbean or Black	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0
Other White British	0	1	2	1	1	5	10	2	0	22	0	3	0	0	0
Pakistani, Pakistani Scottish or Pakistani British	0	0	0	0	0	0	1	0	0	2	0	0	0	0	0
White Irish	0	1	0	1	0	2	1	0	0	1	0	0	0	0	0
White Other	0	0	0	0	3	0	14	1	1	24	0	0	0	0	0
White Polish	0	0	0	0	0	1	0	0	0	2	0	0	0	1	0
White Scottish	10	5	3	20	7	17	87	12	10	59	0	10	1	4	3

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Table 10.4: HIV Self Test Scotland Evaluation - Having Ever Injected Drugs by Health Board

NHS Health Board	No	Yes
NHS Ayrshire & Arran	11	0
NHS Borders	7	0
NHS Dumfries & Galloway	5	0
NHS Fife	24	0
NHS Forth Valley	11	0
NHS Grampian	27	0
NHS Greater Glasgow & Clyde	117	8
NHS Highland	15	0
NHS Lanarkshire	11	0
NHS Lothian	115	6 <sup>j</sup>
NHS Shetland	2	0
NHS Tayside	14	0
NHS Western Isles	1	0
Prefer not to say	6	0
Did not disclose	4	0

<sup>j</sup> One individual reported injecting drugs within the last six months.

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Table 10.5: HIV Self Test Scotland Evaluation – Having Ever Exchanged Sex for Money or Other Goods by Health Board

NHS Health Board	No	Yes
NHS Ayrshire & Arran	11	0
NHS Borders	5	2
NHS Dumfries & Galloway	5	0
NHS Fife	23	1
NHS Forth Valley	10	1
NHS Grampian	25	2
NHS Greater Glasgow & Clyde	108	17 <sup>k</sup>
NHS Highland	12	3'
NHS Lanarkshire	11	0
NHS Lothian	111	10 <sup>m</sup>
NHS Shetland	2	0
NHS Tayside	14	0
NHS Western Isles	1	0
Prefer not to say	6	0
Did not disclose	3	1

<sup>&</sup>lt;sup>k</sup> One individual in NHS Greater Glasgow & Clyde reported having exchanged sex for money or other goods within the last six months.

<sup>&</sup>lt;sup>1</sup> One individual in NHS Highland reported having exchanged sex for money or other goods within the last six months.

<sup>&</sup>lt;sup>m</sup> Three individuals in NHS Lothian reported having exchanges sex for money or other goods within the last six months.

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## Appendix B: Table: Distribution by proximity to a sexual health clinic

 Table 11.1: HIV Self Test Scotland – Distribution by proximity to a sexual health clinic by NHS Health Board

		Distance to Nearest Sexual Health Clinic							
NHS Health Board	TOTAL	Within 5km (Urban)	Within 10km (Semi-Urban)	Within 25km (Semi-Rural)	Outwith 25km (Rural)	Outwith 50km (Remote)	Did not disclose		
NHS Ayrshire & Arran	11	10	1	0	0	0	0		
NHS Borders	8	0	0	5	0	3	0		
NHS Dumfries & Galloway	5	3	2	0	0	0	0		
NHS Fife	21	19	2	0	0	0	0		
NHS Forth Valley	13	6	6	1	0	0	0		
NHS Grampian	26	10	4	8	4	0	0		
NHS Greater Glasgow & Clyde	117	114	3	0	0	0	0		
NHS Highland	17	3	2	4	0	8	0		
NHS Lanarkshire	24	4	9	11	0	0	0		
NHS Lothian	111	108	3	0	0	0	0		
NHS Shetland	2	0	0	0	0	2	0		
NHS Tayside	15	11	1	1	0	2	0		
NHS Western Isles	1	0	0	0	0	1	0		
Did not disclose	13	0	0	0	0	0	13		

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## Appendix C: HIV Self Test Scotland Survey

**Preamble** 

#### What is this survey about?

The purpose of this survey is to evaluate the service provided HIV Self Test Scotland.

We have sent you the survey because you recently ordered a HIV self-test kit from HIV Self Test Scotland. We would like to find out what you liked and didn't like about the service, so that we can improve it in the future.

You can complete the survey whether or not you used the HIV self-test kit. All of the questions are optional and you can skip any that you do not want to answer.

#### Who is running the survey?

HIV Self Test Scotland is running the survey. HIV Self Test Scotland is a partnership between HIV Scotland and Waverley Care.

#### What personal data will the survey collect?

The survey can be completed anonymously, or you can choose to enter personal data (your email address). We will only use your email address to enter you into a prize draw to win an Apple Watch or to contact you about a follow up interview. If you include your email address, you will be asked at the end of the survey if you consent to it being used for both, or only one of, these purposes

#### How will you use the information I provide?

Your survey response will be collated and analysed by staff from HIV Scotland and Waverley Care. We will use the information you provide as part of a report about HIV Self Test Scotland. We will share the evaluation findings publicly, including via social media and in published articles. We will not share any information that could identify you or other people.

#### How will you store the information I provide?

Your survey response will be stored using password protection. Your personal data will be deleted on 31 December 2020 and we will only keep your anonymised survey response.

#### Can I withdraw my survey response?

If you decide you do not want your survey response to be included in the evaluation, you can contact <u>ruth.mckenna@waverleycare.org</u>. If you have completed the survey anonymously, we may not be able to identify your response, but we will try to do this. If we can identify your response, you will be able to withdraw it until the point we publish the survey results, which will be around mid-September.

## Who can I contact if I have questions about the evaluation or I want to make a complaint?

If you have questions about the evaluation, you can contact info@hivtest.scot

If you would like to speak to someone who is not involved in the evaluation, you can contact: Grant Sugden, CEO, Waverley Care <u>Grant.Sugden@waverleycare.org</u>

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#### **Background information**

This section of the survey asks for information about your identity and background.

#### 1. How would you describe your gender?

- □ Male (include trans male)
- □ Female (include trans female)
- □ Non binary
- □ Prefer not to say
- □ In another way, please describe

#### 2. Is your gender the same as the sex you were assigned at birth?

Sex assigned at birth refers to the sex a midwife or other health professional assigned you based on a visual inspection of your genitals after you were born

- Yes
- No
- Prefer not to say

#### 3. What is your age?

- Under 18
- □ 18 24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

#### 4. What are the first three digits of your postcode?

4-character box

#### 5. How would you describe your sexual orientation?

- Gay man
- Gay woman/lesbian
- Bisexual
- □ Heterosexual/straight
- Prefer not to say
- □ In another way
- FREE TEXT BOX

#### 6. In the last 2 years, who have you had sex with?

- Cis men
- Trans men
- Cis women
- Trans women
- Prefer not to say
- Partners who describe their gender in another way, please describe

#### FREE TEXT BOX

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#### 7. In the last 2 years, what kinds of sex have you had?

- Penetrative anal sex
- □ Receptive anal sex
- □ Penetrative vaginal/front hole sex
- □ Receptive vaginal/ front hole sex
- □ Given oral sex
- □ Received oral sex
- Prefer not to say
- □ Another kind of sex, please describe

TEXT BOX

#### 8. How would you describe your ethnicity?

Drop down menu

#### 9. What is your highest educational qualification?

SCQF menu

#### 10. Were you born in the UK?

- □ Yes (Logic: skip to Q13)
- No

#### 11. How long have you lived in the UK

- □ Under 1 year
- □ 1-2 years
- □ 3-4 years
- □ 5-9 years
- □ 10+ years

#### 12. What is your country of origin?

Drop down menu

#### 13. Have you ever injected drugs?

- Yes
- □ No (Logic: skip to Q16)

#### 14. When did you last inject drugs?

- □ Within the last 4 weeks
- □ Within the last 3 months
- □ Within the last 6 months
- □ Within the last 12 months
- □ Within the last 2 years
- □ Within the last 5 years
- Over 5 years ago

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#### 15. What drugs did you inject?

- Heroin
- Cocaine
- Crack cocaine
- □ Methamphetamine (crystal meth)
- □ Amphetamine (speed)
- □ Mephedrone
- Another drug

FREE TEXT BOX

#### 16. Have you ever used drugs during or to enhance sex?

- Yes
- No

#### 17. Have you ever exchanged sex for money or other goods?

- Yes
- □ No (Logic: skip to Q18)

#### 18. When did you last exchange sex for money or other goods?

- □ Within the last 4 weeks
- Within the last 3 months
- Within the last 6 months
- Within the last 12 months
- □ Within the last 2 years
- □ Within the last 5 years
- □ Over 5 years ago

#### PEP and PrEP

This section of the survey asks about your experience of using PrEP and PEP.

*PrEP stands for pre-exposure prophylaxis. PrEP is taken by HIV negative people before sex to protect against HIV. PrEP usually involves two HIV drugs combined in a single pill. For example, Truvada or Tenvir-EM.* 

#### 19. Have you heard of PrEP before?

- Yes
- No

#### 20. Have you ever taken any PrEP (e.g. Truvada or Tenvir-EM)?

- Yes
- □ No (Logic: skip to Q23)

#### 21. Do you currently use PrEP?

- Yes
- $\Box$  No (Logic: skip to Q23)

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#### 22. Where do you currently get your PrEP drugs?

- □ NHS sexual health clinic
- □ From an online pharmacy
- □ In another way, please describe

FREE TEXT BOX

#### 23. When do you take your PrEP drugs?

- Every day
- Just when I need to (event-based dosing)

PEP stands for post exposure prophylaxis. PEP is when an HIV negative person uses HIV medication for a month. It is prescribed after a high HIV risk to prevent infection. For example, if a condom broke with a partner who is HIV positive and not on treatment.

#### 24. Have you heard of PEP before?

- Yes
- No

#### 25. Have you ever used PEP?

- Yes
- $\Box$  No (Logic: skip to Q26)

#### 26. When did you last use PEP?

- Within the last 4 weeks
- □ Within the last 3 months
- Within the last 6 months
- Within the last 12 months
- Within the last 2 years
- Within the last 5 years
- Over 5 years ago

#### HIV and STI testing

This section of the survey asks about your experience of taking HIV and STI tests.

HIV self-testing is when you take a sample, then process the test and interpret the result yourself.

HIV self-sampling (or postal testing) is when you take a sample and post it to a laboratory who process it and return your result.

27. Was the HIV self-test you ordered from HIV Self Test Scotland the first time you have taken an HIV test (including Self Testing/sampling or having a test done by a medical professional) ?

- □ Yes (Logic: skip to Q30)
- □ No

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#### 28. When did you last take an HIV test?

- □ Within the last 4 weeks
- Within the last 3 months
- □ Within the last 6 months
- □ Within the last 12 months
- □ Within the last 2 years
- □ Within the last 5 years
- □ Over 5 years ago

#### 29. How many HIV tests have you taken in the last 12 months?

Number only box

## 30. Excluding your most recent test from HIV Self Test Scotland, where have you tested in the last 12 months (please tick all that apply)?

□ GP

Sexual health clinic

Community testing service (a testing service not based in an NHS or private health facility)

- Hospital
- □ I used a self-sampling kit (I took a sample and sent off for the results)

□ I used a self-test kit from HIV Self Test Scotland(I took a sample and found out the results on the spot)

□ I used a self-test kit from another provider (I took a sample and found out the results on the spot)

□ Another location, please describe FREE TEXT BOX

## 31. When did you last have a test for sexually transmitted infections (STIs), such as syphilis and gonorrhoea?

- □ Within the last 4 weeks
- Within the last 3 months
- □ Within the last 6 months
- Within the last 12 months
- □ Within the last 2 years
- □ Within the last 5 years
- Over 5 years ago
- Never (Logic: skip to Q33)

#### 32. Have you been diagnosed with any STIs in the last 2 years?

- Yes
- □ No (Logic: skip to Q33)

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#### 33. Which STIs were you diagnosed with?

- Gonorrhea
- Chlamydia
- □ Non-specific urethritis (NSU)
- Genital warts
- Herpes
- Syphilis
- Hepatitis B
- Hepatitis C
- □ Other
- I don't know

#### Your HIV-self test

This section of the survey asks about the self-test you recently ordered from HIV Self Test Scotland

#### 34. Do you think you may have been at risk of contracting HIV?

- Yes
- $\Box$  No (Logic: skip to Q35)
- Not sure

#### **35. Why do you think you may have been at risk of contracting HIV?** FREE TEXT BOX

#### 36. What made you decide to order an HIV self-test kit?

- Peace of mind
- □ I want to know my status
- Routine test
- □ New relationship/sexual partner
- □ It's the only testing service I could access
- Advised to get tested
- □ Ability to test from home
- □ It's a free service
- Convenience
- Privacy
- Travel purposes (i.e. condition for a travel visa)
- Prefer not to say
- □ For another reason, please describe

FREE TEXT

#### How much do you agree with the following statements?:

#### 37. 'I was able to order the HIV self-test kit without any problems'

- □ Strongly agree
- □ Agree
- Neither agree or disagree
- Disagree
- Strongly disagree

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#### 38. 'I received the HIV self-test kit without any problems'

- Strongly agree
- Agree
- □ Neither agree or disagree
- Disagree
- Strongly disagree

#### 39. Would you like to share any other feedback on the ordering process?

#### FREE TEXT BOX

#### 40. Did you use the kit to test yourself?

- □ Yes (Logic: skip to Q41)
- No

#### 41. Why not?

- □ I tested somewhere else instead
- □ I didn't know how to use the test
- □ I changed my mind about self-testing
- □ The instructions were too difficult
- □ I gave the test to someone else
- □ Not yet, but I still plan to use it later
- Another reason, please describe

FREE TEXT BOX (Logic, all responses: skip to Q54)

## 42. What instructions did you use to take the self-test kit? (please select all that apply)

- Biosure HIV self-test video
- □ The paper instructions enclosed in the test
- Guidance on HIV Self Test Scotland website
- □ I didn't use instructions (Logic: skip to Q43)

#### How much do you agree with the following statement?

#### 43. 'The instructions were easy to use'

- □ Strongly agree
- □ Agree
- □ Neither agree or disagree
- Disagree
- □ Strongly disagree

## Thinking about the self-test kit, how much do you agree with the following statements?

#### 44. 'Performing the test was simple'

- □ Strongly agree
- Agree
- □ Neither agree or disagree
- □ Disagree
- □ Strongly disagree

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#### 45. 'My overall experience with the self-test kits was good'

- □ Strongly agree
- □ Agree
- □ Neither agree or disagree
- Disagree
- Strongly disagree

## 46. Would you like to share any other feedback on the process of using the HIV self-test kit?

#### FREE TEXT BOX

#### 47. What was the result of your HIV self-test?

- Positive
- □ Negative (Logic: skip to Q54)
- □ The test didn't work (Logic: skip to Q53)

#### 48. Have you been to a clinic or doctor to have this result confirmed?

- No
- Yes and the result was positive (Logic: skip to Q50)
- □ Yes and the result was negative (Logic: skip to Q54)

# 49. It is very important that you contact a clinic or a doctor to have your HIV diagnosis confirmed. Would you like someone from our team to contact you to discuss your result and help you to access a confirmation test?

- Yes
- $\Box$  No (Logic: skip to Q59)

## 50. Please include your contact details and someone will be in touch with you. FREE TEXT BOX

#### 51. Are you now under the care of an HIV clinic or doctor?

- □ Yes (Logic: skip to Q59)
- No

52. It is very important that you receive care from an HIV clinic or doctor. Would you like someone from our team to contact you to discuss your result and help you to access HIV care?

- Yes
- $\Box$  No (Logic: skip to Q59)

## **53.** Please include your contact details and someone will be in touch with you. FREE TEXT BOX (Logic: skip to Q54)

54. Please give more details FREE TEXT BOX

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#### HIV self-testing in the future

This section of the survey asks for your views on using HIV self-testing again.

#### 55. Would you order an HIV self-test from HIV Self Test Scotland again?

- Yes
- No
- I don't know

#### 56. How would you prefer to self-test in the future?

- □ Using a blood sample
- Using a saliva sample
- Neither blood nor saliva

## 57. If it was only available at cost, how much would you be willing to pay for an HIV self-test kit?

- Postage costs
- £5
- □ £10
- □ £15
- £20
- I wouldn't use the service if I had to pay

#### 58. In which of the following ways would like to be able to receive self-test kits?

- Postal delivery from online order
- □ From sexual partners
- □ Via outreach workers in community settings
- □ Via vending machines
- □ Via click-and-collect (order online and collect from a charity, clinic or pharmacy)
- Collect via a community organisation
- Collect via a sexual health clinic
- □ Collect via a pharmacy

## 59. In the future, what kind of support would you want when using HIV self-testing kits?

- □ Video / online counselling
- □ Other online support
- Dedicated phone line
- □ Face-to-face advice (from a health advisor or outreach worker for example)

□ No support is needed beyond that available already by attending a sexual health clinic

Another type of support, please describe

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#### **HIV Self Test Scotland**

This section of the survey asks for your opinions about the HIV Self-Test Scotland service.

#### 60. Did you contact HIV Self Test Scotland before or after ordering a self-test kit?

Yes

No (Logic: skip to Q65)

#### 61. Why did you get in contact with HIV Self Test Scotland?

□ To ask a question about the delivery process (for example, packaging or delivery timescales)

- □ To ask about a delayed order
- □ To ask about the effectiveness of self-testing or the window period
- □ To ask for help with carrying out the self-test
- □ To report that a self-test had not worked
- □ To ask for help with interpreting the self-test result
- □ To discuss a negative result
- □ To discuss a positive result
- Another reason, please describe

FREE TEXT BOX

#### 62. How did you contact HIV Self Test Scotland?

- Live chat function
- Website contact form
- □ Telephoning Waverley Care
- □ Telephoning HIV Scotland

## Thinking about your experience of contacting HIV Self Test Scotland, how much do you agree with the following statements:

#### 63. 'I was able to get in touch with HIV Self Test Scotland quickly'

- □ Strongly agree
- □ Agree
- □ Neither agree or disagree
- Disagree
- Strongly disagree

#### 64. 'HIV Self Test Scotland provided me with the help or advice I needed'

- □ Strongly agree
- □ Agree
- □ Neither agree or disagree
- Disagree
- □ Strongly disagree

## 65. Would you like to share any other feedback on the process of getting in touch with HIV Self Test Scotland?

#### FREE TEXT BOX

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## 66. Based on what you know now, would you recommend HIV Self Test Scotland to other people?

- Yes
- 🗆 No
- Not sure

## 67. Is there anything else you would like to share about your experience of using HIV Self Test Scotland?

#### FREE TEXT BOX

#### End of survey message

Thank you very much for taking the time to complete this survey. Your responses will help us to develop and improve HIV Self Test Scotland.

If you would like to be entered into a prize draw to win an Apple Watch please provide your email address below:

#### FREE TEXT BOX

This survey is one part of a wider evaluation of HIV Self Test Scotland. We also plan to carry out one-to-one interviews with people who have used the service. Interview participants will receive a £15 voucher in recognition of their time and contribution. The interview will last around an hour and take place over the phone or on Zoom.

If you would be willing to take part in an interview, please provide your email address below:

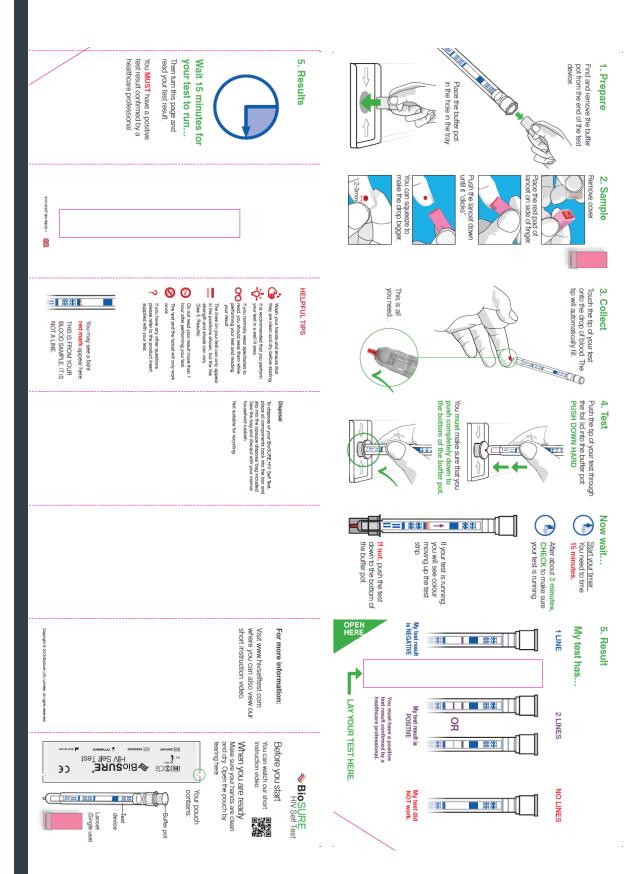
#### FREE TEXT BOX

If you would like further support with any of the issues raised in this survey, you can contact us in a number of ways. You can speak to one of our live chat advisors by visiting: <u>https://www.hivtest.scot/contact</u>. This service is available 10am - 4pm Monday, Tuesday, Thursday and Friday.

You also can send us an offline message outside of these hours. You can also get in touch by calling: Waverley Care on 0131 441 6989, 9am – 5pm every day. HIV Scotland on 0131 558 3713, from 9pm - 5pm, Monday to Friday

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## Appendix D: Biosure<sup>™</sup> HIV Self-Test Instructions



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