

A final update on the SELPHI study

In 2017 or 2018 you agreed to take part in a study of HIV self-testing called SELPHI. You might have been one of the lucky ones who received one of more free HIV self-tests through the study. Or you might have only been asked to complete surveys. Either way, we are extremely grateful to you for taking part. You've given us very valuable information which will help the NHS and public health authorities decide the best ways to offer HIV testing.

This final newsletter tells you what we did in SELPHI and what the main results were.

Briefly, we found that offering people the chance to order a free HIV self-test increased the number of people who tested for HIV. Despite this success, we weren't able to directly show that it made a real difference to how quickly people were diagnosed and linked to medical care. This is probably because rates of new HIV infections were much lower than we expected when we planned the study in 2015.

We'd also like to invite you to a **participant webinar on Thursday 8th July, 6-7pm**. We will talk about the results in more detail, and give you the opportunity to ask any questions about the study you may have. We had originally planned to have a participant meeting in London, but were unable to move forward with this plan due to the COVID-19 pandemic.

The platform we are going to use is Zoom. We are planning a brief recap of why the trial was done, the results in more detail, findings from the qualitative parts of the study, and discussion about the implications of the findings. There will be some time for questions and comments. **The webinar will not be recorded and you can remain anonymous if you want.**

Please use the link below to register for the webinar that will take place on Thursday 8th July, 6-7pm. Your name and email address will be required to register on Eventbrite and it will be used to send you the link to join the webinar on the day. This information will only be visible to the organiser at the MRC CTU at UCL.

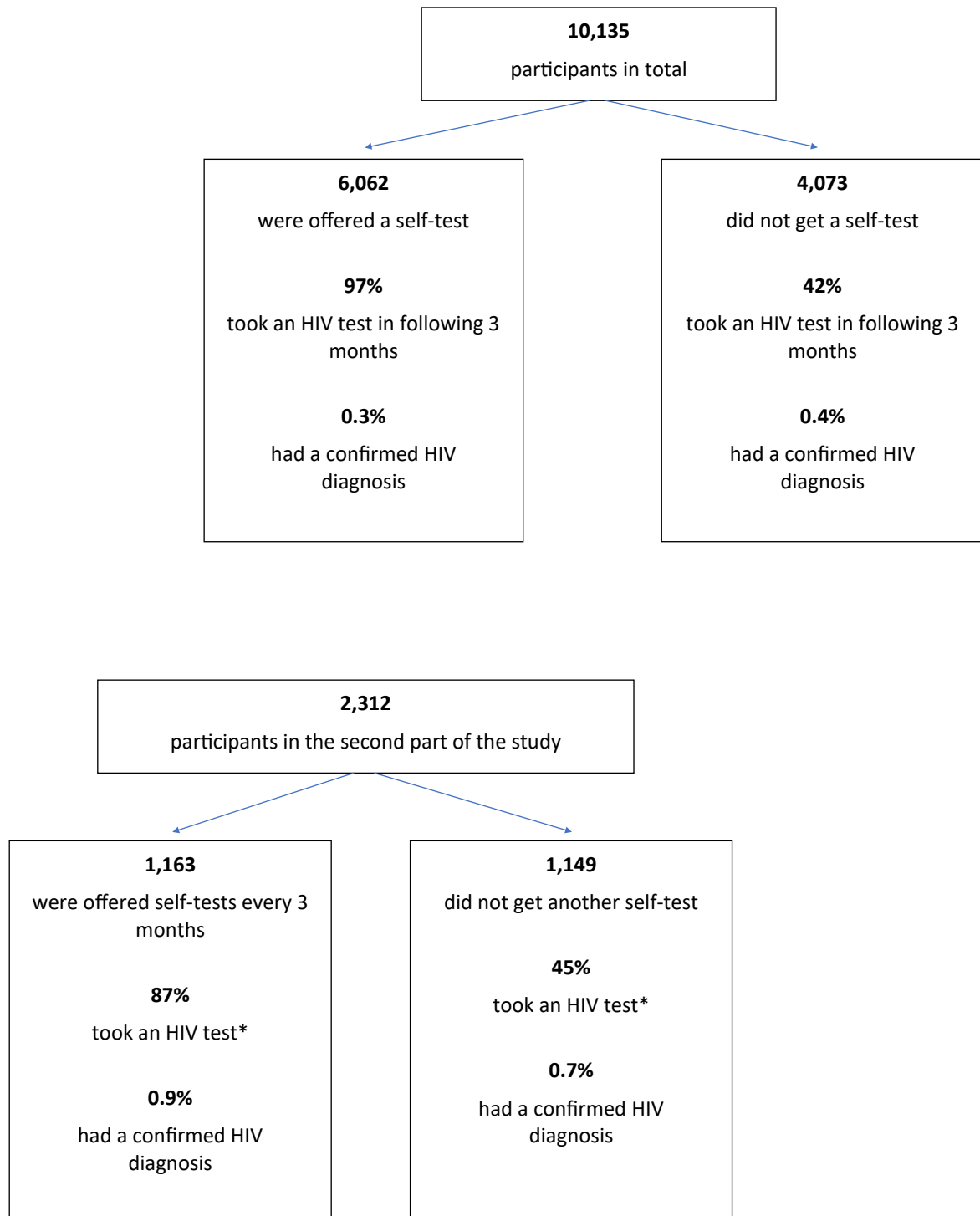
<https://www.eventbrite.co.uk/e/selphi-participant-webinar-tickets-157244174559>

We look forward to seeing you at the webinar!

Best wishes and stay safe,

The SELPHI Team

Results at a glance



**Participants were sent surveys every 3 months. This figure is the average HIV testing rate in the previous three months before a survey.*

What were we trying to find out?

SELPHI was done to find out if offering free self-testing can help people get tested and be tested more often. We wanted to see if this could lead to people being more likely to be diagnosed if they become HIV positive.

This is important because over a quarter of gay and other men who have sex with men (MSM) in the UK have never tested for HIV. Also, only a quarter of those considered to be at higher risk of HIV test at least every six months. As a result, many people are diagnosed late, when HIV has already started to affect their health.

SELPHI enrolled gay and other men who have sex with men (MSM), including both cis MSM (not trans) and trans MSM. In addition, we included trans women who have anal sex with men, whose experiences are likely to be different from MSM. There is very little information on HIV testing among trans men and trans women in this country.

Who took part?

Between February 2017 and February 2018, a total of 10,135 people responded to adverts on Facebook, Grindr, Scruff, Growlr and other websites, and joined the SELPHI study.

Everyone who took part was aged 16 or over, lived in England or Wales, had had anal sex with a man, and had not been diagnosed with HIV at that stage.

There were 10,041 cis men, 94 trans men and 24 trans women.

Half the participants were aged between 26 and 44, 80% were born in the UK and 89% were White. 42% finished education at 16 or 18 years, while 47% had gone to university.

In the three months before the first survey, 28% had not had anal sex without a condom, 33% had had it with one partner, 29% with two to four partners, and 10% with five or more partners.

Only 4% were taking PrEP at the time.

In terms of HIV testing, while 54% of people in the study had taken a test in the previous year (including 33% who had tested within six months), 31% had last tested more than a year ago and 15% had never taken a test.

Everyone who took part was sent a number of surveys during the study, though some were asked to complete more surveys than others. For most surveys, around half of participants responded and one survey was completed by 84% of people. We are very grateful for the time you took to complete these surveys and help us answer our research questions around HIV self-testing.

How SELPHI checked how many people were diagnosed with HIV

The main aim of SELPHI was to see if offering free HIV self-tests would have an impact on how quickly after becoming HIV positive people had a confirmed HIV diagnosis at a clinic. We didn't just want to see whether offering HIV self-tests resulted in people testing more frequently, but also to see if we could directly show that it helped people with undiagnosed HIV connect with a clinic and get the medical care they need.

Everyone who took part gave permission for some of their personal information to be used to find out if they had been diagnosed with HIV at a clinic in the UK.

To do this, SELPHI checked a database of all people diagnosed with HIV which is held by Public Health England (PHE). We used information such as your postcode, date of birth, initials and a coded anonymised version of your surname. We also looked at the information you gave in the surveys about whether you had tested positive.

Main results from the first part of SELPHI

In the first part of the study, everyone taking part was allocated to either be offered one free HIV self-test, or to not receive one. You were all put into different groups by chance, by a process called randomisation. This was a bit like tossing a coin. This process gives us the best quality results because it means that, as a whole, the group given the self-tests were very similar to the people not given the tests. This means that any differences we saw between the two groups is likely to be due to us offering the tests and not the fact that the groups were different to start with.

There were 6062 people in the group who got one self-test and 4073 in the group who did not receive a self-test.

If you were in the second group, you may have been disappointed. Nonetheless, the information you gave us was vital. For the study to work, we needed to compare a group that received a test with a group that did not.

Your answers to surveys helped us understand the benefits of getting a self-test. Almost everyone who received one used it and 97% had taken at least one HIV test within three months of enrolling. This compares to 43% in the other group – people who didn't receive a self-test from SELPHI used other services and clinics to get an HIV test.

But the key thing we were looking for was confirmed HIV diagnoses. In this part of the study we hoped that self-testing might help people who had had HIV for some time without realising it be diagnosed and linked to care.

In fact, the number of new HIV diagnoses was quite low in both groups (which is overall very good news). There were 19 diagnoses in 6062 people who received a self-test (equivalent to 0.3%). This was not different to the 15 diagnoses in 4073 people who did not get a self-test (0.4%).

Main results from the second part of SELPHI

The study had a second part. This only involved people who had received a self-test in the first part and who said in surveys that they had recently had anal sex without a condom. This group was selected because they were likely to be at greater risk of acquiring HIV.

This time, study participants were allocated to either be offered regular, repeat self-tests, or not to be given another self-test. Again, people were randomly allocated to the groups by chance. The 50% of people who were put in the group for regular tests could order an HIV self-test every three months for up to two years. In this stage, we hoped that self-testing would help *new* HIV infections be diagnosed.

There were 2312 participants who were eligible for this part of the study and this was fewer than we had expected. Also, as in the first part of the study, the overall rate of new HIV diagnoses was lower than we had expected when planning the study.

There were 10 diagnoses in people offered regular self-tests (equivalent to 0.9%) and 8 diagnoses in people who didn't get another self-test (0.7%). While this might look as if there was a small benefit to self-testing, in statistical terms it could be a chance result. The numbers of diagnoses aren't large enough for us to be sure it reflects a real benefit.

Low numbers of HIV diagnoses—does this explain the results?

Between 2014 and 2018, the rate of new HIV infections in men who have sex with men in the UK fell by two-thirds. This is definitely good news, but it did make it harder for a research study like SELPHI to have a clear result.

These falls in HIV are thought to be due to a combination of increased rates of HIV testing, people starting HIV treatment quickly after diagnosis (effective treatment reduces the transmission risk through sex to zero) and the prevention medication PrEP (pre-exposure prophylaxis).

Planning a study like SELPHI involves estimating how many people would need to take part and for how long to be likely to come up with a result. This is based on assumptions about what proportion of people may become HIV positive and how long it may take them to be diagnosed. We had planned for various possible scenarios, but the rate of new HIV infections fell well below the levels that we had calculated for.

To put it simply, if an infection is spreading rapidly, it does not take long for a study to prove that an effective intervention works. An example is studies into COVID-19 vaccines, which have only taken a few months. Thankfully, HIV is now spreading more slowly, but this makes studies harder to do.

It's possible that a study with more people taking part or which provided regular self-tests for longer would have shown that people are diagnosed more quickly, but we can't be sure.

Other things we've learned from SELPHI

As well as the headline results, the information you gave us has resulted in lots of other important findings:

- Most people found the ordering process and self-testing kit easy to use. You had a mix of reasons for using self-testing: many people felt it removed barriers to testing and offered a more private and convenient alternative to clinic services. Some of you felt there was a stigma in using sexual health clinics, or there simply wasn't one close to where you live. Some of you used self-tests as a way to test more frequently.
- Only around 1% of people who filled in surveys described any harms or negative experiences related to HIV self-testing. These rare experiences included being pressured to test, dealing with inaccurate results, arguments with a partner, and the breakdown of a relationship.
- One worry about HIV self-testing is that because testing for chlamydia, gonorrhoea and other STIs is not provided with an HIV self-test, people using them might miss out on these important tests. But your survey responses didn't suggest this was a problem – many people continued to get STI tests in other ways.
- Not many SELPHI participants used PrEP and many people had sex without condoms with multiple partners. But people who received HIV self-tests didn't seem to have more risky sex than other people in the study.
- Self-testing might have particular benefits for trans people, as most sexual health services do not meet their unique needs. There weren't many trans participants in the study, but there were especially large increases in the uptake and frequency of HIV testing among the trans participants who got self-tests. No trans participants were diagnosed with HIV during the study.
- Self-testing was also popular with Asian, Black and Latin American men, who sometimes feel excluded from the gay scene and may miss out on health information that circulates there. Many men we spoke to experienced discomfort in the waiting rooms of sexual health services. The privacy and confidentiality of HIV self-testing may be particularly valued by men of minority ethnic backgrounds.
- Many people had not recently taken an HIV test when they joined the study, including many people who had recently had sex without a condom with more than one partner. This showed the importance of developing new HIV testing services, perhaps including self-testing.
- Your strong interest in taking part in SELPHI and the high uptake of repeat testing in the second part of the study shows that there is a lot of interest in HIV self-testing.

Unanswered questions

As we continue to analyse the results and their implications, the research team have a number of questions. We'd be interested in your opinions about these points and any other aspects of the study. These are some of the issues we'll discuss at the webinar on the 8th July (see first page for details).

Apart from the falling rate of HIV infections, do you think there are other reasons why the study did not show that HIV self-testing helped people be diagnosed more quickly? Are there other possible explanations for the results?

Were the study participants representative enough of the gay and other men who have sex with men who are at greatest risk of HIV? While it was important for us to recruit a diverse group of participants, this needed to include people who will benefit the most from better access to HIV testing. Did we achieve this?

What do the results of the study mean for the availability of self-testing in the UK? Does the study provide enough evidence to convince the NHS and public health officials to provide HIV self-testing?

If self-testing is more widely used for HIV, how should testing for other sexually transmitted infections be provided?

Taking an HIV test

If you are looking for somewhere to test, you have several options based on where you live:

You can use the **NAM test finder** [here](#) to locate your nearest clinic or community-based testing option.

People living in many parts of England can access the **national HIV self-sampling service**. You can check availability by visiting [their website](#).

If you would like to **purchase a self-test**, you can do so through the [BioSURE website](#). You can also **request an HIV test from your GP**.

If you would prefer to speak to someone about the different testing options available in your area, you can call **THT Direct** at 0808 802 1221.

Get in touch with us!

What do you think of our work so far? Please contact us with your thoughts and suggestions:

Email: mrcctu.selphi@ucl.ac.uk

The study is being delivered in partnership with community representatives. You can find out more information on who they are on our website: <http://www.selphi.org>