Sephi An HIV Self-testing Public Health intervention

This document contains additional information about the SELPHI study that you might want to know

What does SELPHI stand for?

SELPHI stands for "An HIV <u>Sel</u>f-testing <u>public</u> <u>h</u>ealth <u>i</u>ntervention."

What are we trying to find out?

SELPHI is trying to find out if offering free self-testing can help people get diagnosed with HIV more quickly. We are enrolling gay and other men who have sex with men (MSM), and this includes both cis MSM (not trans) and trans MSM. In addition, we want to include trans women who have sex with men whose experiences are likely to be very different from MSM.

The results from SELPHI will help the NHS decide if it should provide free HIV self-testing. It will look at the cost as well as benefits of self-testing when deciding this.

Why is SELPHI looking for men, trans men and trans women who have sex with men?

This is because these groups have a higher risk for HIV than the general population. That said, there is very little information on HIV among trans men and trans women in this country.

We estimate that most new HIV infections come from people who don't know they are infected. Research shows that on average only about half of gay men with HIV in the UK are diagnosed within 2 years of getting infected. During this time, they may expose several partners to HIV without realising it. If people are tested more frequently it might shorten the time that people don't know they are infected. This should reduce the number of new infections and improve the health of those who get HIV.

Why doesn't everyone get a self-test?

Some participants will not get any free self-test kits. This is because we need to compare a group that receive a test with a group that do not to see if offering self-tests shortens the length of time that people don't know they are infected. The information given to us by all SELPHI participants is vital, whether or not they get any self-test kits.

People will be put in to different groups by chance, by a process called randomisation. This is a bit like tossing a coin.

In SELPHI:

- 60% of participants will receive at least one free HIV self-test kit. Some participants will be offered more free kits at a later date.
- 40% of participants will not receive a free HIV self-test kit. Participants will be given advice on how to access testing elsewhere.

Will I be able to still get tested at my sexual health clinic?

Yes, you can still visit your sexual health clinic at any time. Actually, it is very important that you continue to do this if you need to, including having regular STI tests.

What will be involved with taking part in SELPHI?

It involves several short (5-10 minute) surveys. All surveys are answered online - by phone, tablet or computer. The surveys ask about HIV and STI testing. They also ask about your sex life. People getting self-tests will have additional surveys.

What happens if I test positive?

Some people will test HIV positive. Sometimes this might be a false positive (i.e. a test error). Most often it will mean that you are HIV positive.

If you get a positive result you should arrange to visit a clinic or GP to get your result confirmed. All positive results need to be confirmed by a laboratory test. You can also phone for support to interpret the results or if you are worried about being HIV positive.

It can be a shock to get a positive result, so you will need support. The earlier you find out, the better this is for your health. Everyone in the UK has free access to monitoring and treatment for HIV, even if they are not a resident. HIV treatment is very effective and life expectancy is now close to life expectancy for people who are HIV negative.

What if I have a complaint or some other problem while taking part?

If you would like to discuss anything about SELPHI with someone please contact the team by following the "Contact Us" link in your email or on our website <u>www.selphi.org</u>.

How many participants will be taking part in SELPHI?

SELPHI will enrol 10,000 participants.

How long will SELPHI run for?

SELPHI will last around 2-3 years. We hope that 10,000 participants will have joined by mid- or late-2017. Final results will be available by early 2020.

Can I be paid for taking part in SELPHI?

No. There is no funding to pay people to take part.

Can I stop taking part after I've joined?

Yes, as with all research, it is your choice to take part. You can leave SELPHI if you change your mind. At any time, you can stop completing surveys, stop receiving test kits (if you were going to receive any) or unsubscribe from all messages about SELPHI.

You do not have to provide a reason if you want to leave. This will not affect your other health care. If you are happy to tell us about the reasons, this would help us improve SELPHI.

What will happen to the information from the surveys?

All of your information will be stored on a secure database and will be treated confidentially. Your personal details (surname and date of birth) will be used to match up our data with data held about you on national databases at Public Health England. The answers you give to surveys will not be linked to your personal information.

If you are offered a free self-test kit, BioSURE will not share your address details with anyone else and will not pass on or use your address for any other purpose. The SELPHI Team will not know your address.

What are the possible benefits of taking part?

Some people in SELPHI will receive a free HIV selftest kit. This would otherwise cost £30. Some people might prefer the experience of testing on their own or with someone they trust, instead of having to go to a clinic.

Some people may be offered more free kits in future.

You will have the chance to contribute to this important question looking at how to reduce HIV in the UK. Everyone in SELPHI will be helping the

NHS decide whether self-tests should be available free in the future

What are the possible disadvantages of taking part?

There are very few disadvantages from taking part in SELPHI.

One is that you might not like the experience of self-testing. For example, you might find that you prefer to test in a clinic, where you can talk about the test and the results. However, even if you are sent a free self-test kit you can also test at a clinic whenever you want to.

How can I find out the results of SELPHI?

The main results are not expected until SELPHI finishes. We will tell you about any important findings as we progress.

If you have signed up to the SELPHI mailing list, we may use this to tell you about any updates. Otherwise, we will make the updates available on our website.

The final results from SELPHI and these updates will also be posted on our website. The results will be presented at scientific meetings and published in a medical journal. In these presentations and reports, no individual will be identified in any way. None of your personal information will be reported or published.

What if SELPHI changes or closes early?

This is a possibility in all studies. If there are significant changes to SELPHI, or it needs to close earlier than expected, we will let you know as soon as we can (as long as we can still contact you).

Who is running SELPHI?

SELPHI is run by a number of groups with lots of experience in HIV research.

- MRC Clinical Trial Unit at UCL,
- <u>Department of Infection & Population</u> <u>Health at UCL</u>
- <u>Royal Free London NHS Foundation Trust</u>

- <u>Sigma Research at London School of</u> <u>Hygiene and Tropical Medicine</u>
- Public Health England.

We have also had input from

- <u>HIV i-Base</u>
- SELPHI Community Advisory Board (CAB) which is made up of independent community members
- UK HIV CAB

Who is funding SELPHI?

SELPHI is funded by the <u>National Institute for</u> <u>Health Research (NIHR)</u>.

The manufacturer of the self-test kits (BioSURE), is providing kits for SELPHI at a reduced price. They have no input into the design of SELPHI or the analysis and presentation of the results.

Who has reviewed SELPHI?

SELPHI has been reviewed and approved by the UCL Research Ethics Committee. This review is to protect your safety, rights and well-being.

A community advisory board has advised on the design of SELPHI and the participant materials. This group included cis gay and other MSM, trans men and trans women who are interested in HIV prevention. It also included representatives from several HIV charities and community organisations. The study was also reviewed by the UK HIV CAB.

An independent patient representative at the MRC Clinical Trials Unit at UCL has also helped review the design of the study and the information materials.

Who can I contact for more information?

Visit our website: <u>www.selphi.org</u> Contact us: <u>Click Here</u> SELPHI Community Advisory Board Mailing List Sign Up