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Surveillance of HIV Acquired Recently: Enhanced (SHARE)

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Public Health
England

BHIVA 
British HIV Association

Declaration of Interests relating to this presentation

None

What is SHARE?

Surveillance of **H**IV **A**cquired **R**ecently: **E**nhanced

AIMS:

- Understand recent seroconverter cohort **demographics**
- Gain insight into sexual behaviour preceding **diagnosis**
- Understand **circumstances** leading to seroconversion
- Identify **barriers to HIV prevention options**
- Monitor **PrEP failures/breakthroughs**



How do we identify recent seroconverters?

Recent seroconverter



- **Negative HIV test** result in **30-365d prior** to diagnosis date
AND/OR
- Positive **RITA recent** test

RITA +




PHE HIV datasets:

- Genitourinary Clinic Activity Dataset (**GUMCAD**, monthly and quarterly submissions)
- HIV & AIDS reporting system (**HARS**, quarterly submissions)
- **IMPACT trial** discontinuations

How are the data collected?

- Notify clinicians
- Clinician completes form, invites patient to complete questionnaire (online or paper)

Clinician SHARE form

1.  **CONFIDENTIAL**

Investigation into people with evidence of recent HIV seroconversion

NOTIFICATION FORM - TO BE COMPLETED BY CLINIC STAFF

Public Health England is undertaking enhanced surveillance of all patients who have evidence of recent HIV seroconversion. This includes all newly diagnosed people who have had a **negative HIV test within 12 months of their HIV positive test result or a RNA positive test.**

This information will help us better understand the circumstances under which people acquire HIV. Clinic staff should notify PHE of all patients who seroconvert by completing the details below. This information will allow us to classify the seroconversion into one of the following:

- Seroconverter with PrEP history, possible PrEP failure: patient has a history of PrEP use since last negative HIV test, reports high adherence
- Seroconverter with PrEP history, unlikely PrEP failure: patient has a history of PrEP use since last negative HIV test, reports insufficient adherence or having stopped using PrEP
- Seroconverter with no PrEP history, PrEP offered but declined: patient has no history of PrEP, use was offered PrEP in the past and declined
- Seroconverter with no PrEP history, no PrEP opportunity known: patient has no history of PrEP use and does not report having ever been offered PrEP


Staff should invite patients to complete the questionnaire provided in paper form or available online. However, this notification form is to be completed irrespective of whether the patient completes the questionnaire.

If the patient chooses to complete the questionnaire online, please give the patient a survey invitation card with details of the link to the questionnaire (<https://survey.phe.org.uk/survey>) and their patient clinic ID number.

If the patient chooses to complete the questionnaire on paper, please give them a prepaid PHE addressed envelope with the questionnaire. The survey invitation cards, paper questionnaires and prepaid envelopes have been supplied to your clinic by PHE. If you have any queries regarding this please email shareqa@phe.gov.uk

*Short:
demographics,
PrEP use prior
diagnosis*

Patient SHARE form

2.  **CONFIDENTIAL** Patient Clinic ID No:

Protecting and improving the nation's health.

PATIENT QUESTIONNAIRE

For people with evidence of HIV seroconversion

This questionnaire is for people who have evidence of a recent HIV infection. This means having had a negative HIV test within 12 months of your HIV diagnosis or a positive RNA test. This survey is being conducted by Public Health England in response to the recent falls in new HIV diagnoses. We want to better understand why that is happening to inform HIV prevention activities.

The information you provide is confidential and will help us better understand the circumstances under which people acquire HIV in England. Participation is voluntary and will have no effect on your treatment.

Your answers will not be seen by the doctors and nurses in the clinic and your treatment will not be affected in any way. To help ensure your information stays confidentially we don't collect names or addresses. Instead, the clinic ID provided at the top of this page will be used to link the questionnaire data to the HIV diagnosis record held at Public Health England. The information gathered from questionnaires will be analysed anonymously and will not be shared with third parties. Public Health England will delete these data after 5 years.

The questionnaires will be forwarded to Public Health England by the clinic staff (if you complete it at the clinic) or you can post it to Public Health England using the pre-paid envelope. Please ensure your clinic ID number is provided above.

You can also access this questionnaire online at:
<https://survey.phe.org.uk/survey>

If you would like to withdraw in future, you can tell your clinic to tell us to remove your record at any time.

Please tick the box or write in your answer. Please try and answer all of the following questions.



*Longer,
sexual behaviour,
testing history,
PrEP history,
drug use
how patient acquired
HIV*

SHARE data to date

January 2018- November 2020

511 seroconverters identified from GUMCAD & IMPACT notifications

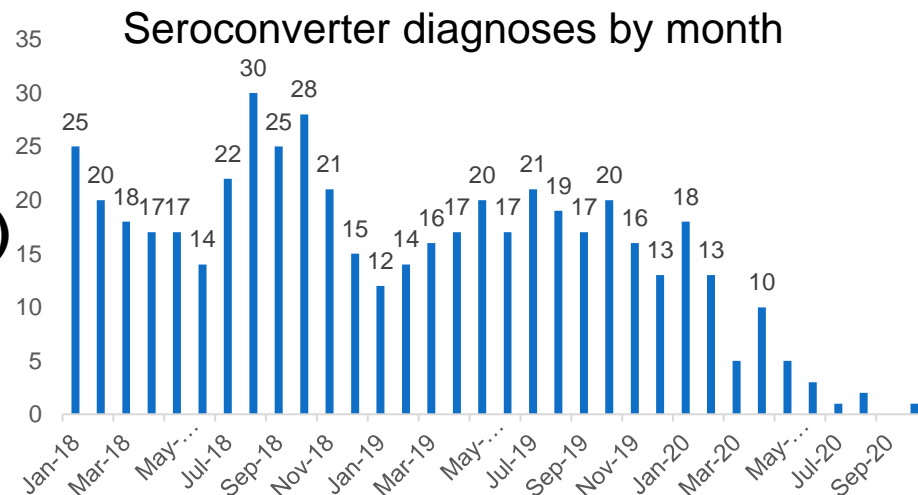
311 SHARE returns

Overall response rate : **60%**

Clinic questionnaires: **59% (n=299)**

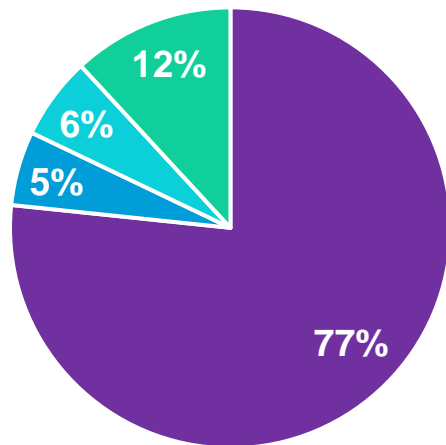
Patient questionnaires: **9% (n=48)**

Both: **7% (n=36)**



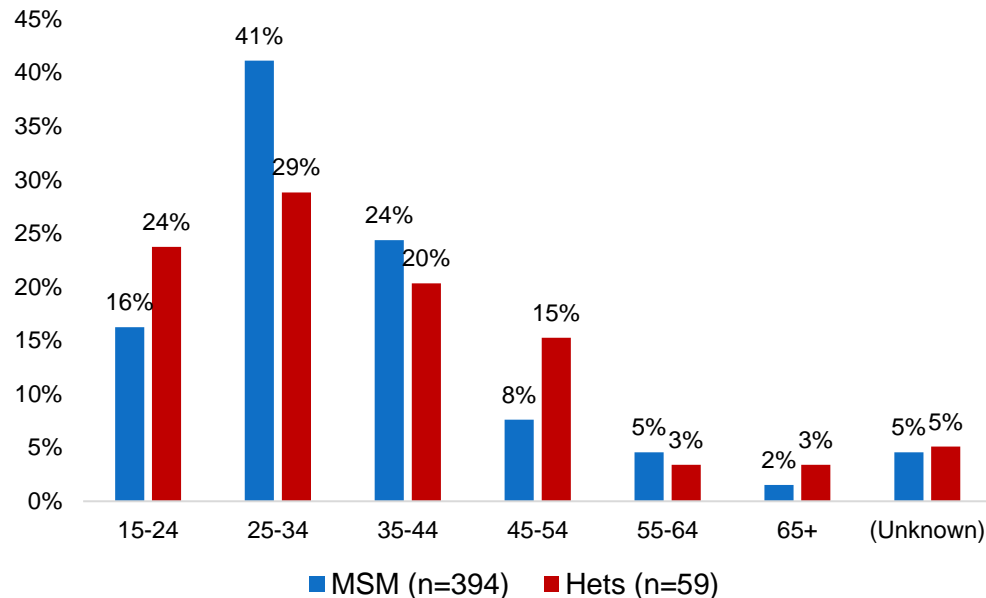
Overall SC demographics (1)

Sexual orientation



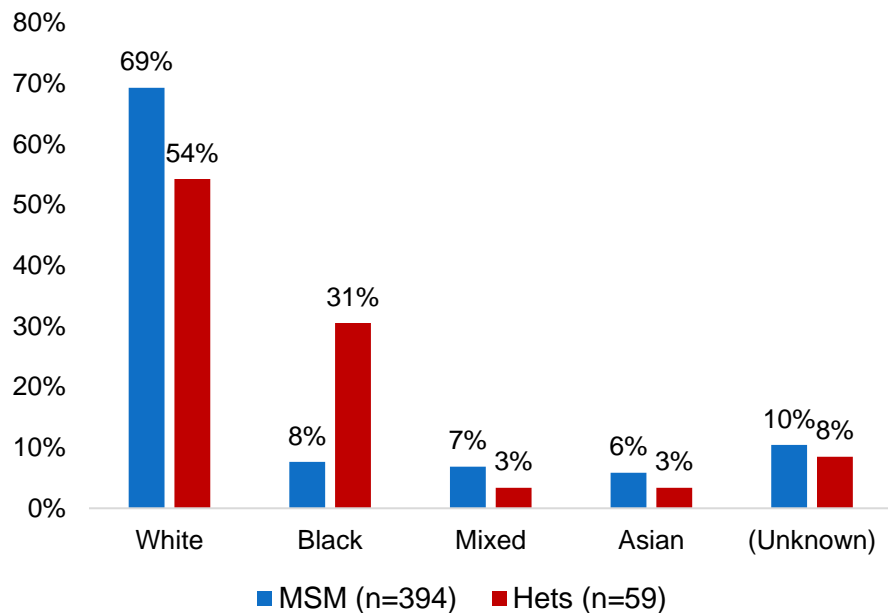
- MSM (n=394)
- Heterosexual men (n=28)
- Heterosexual women (n=31)
- (Unknown)

Age group

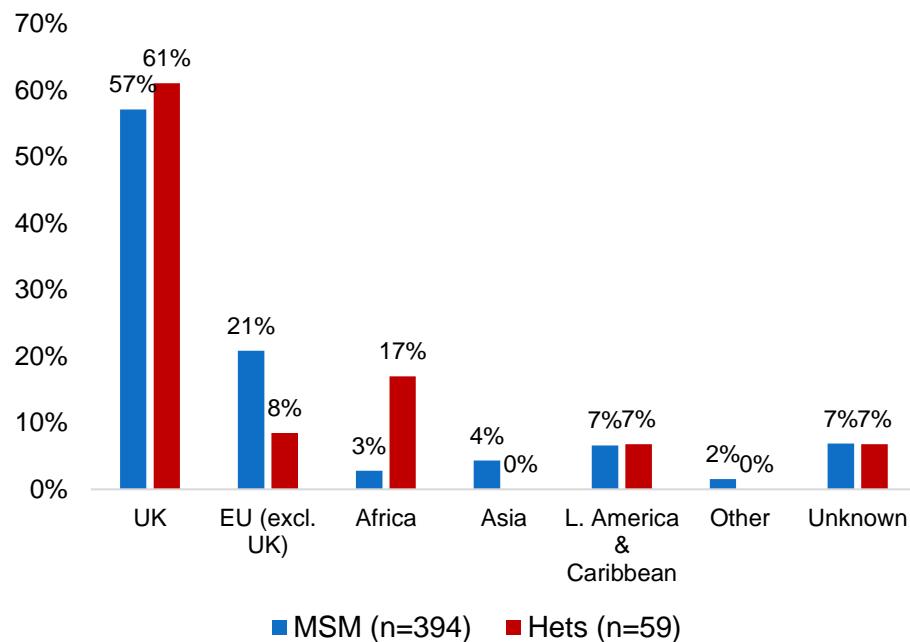


Overall SC demographics (2)

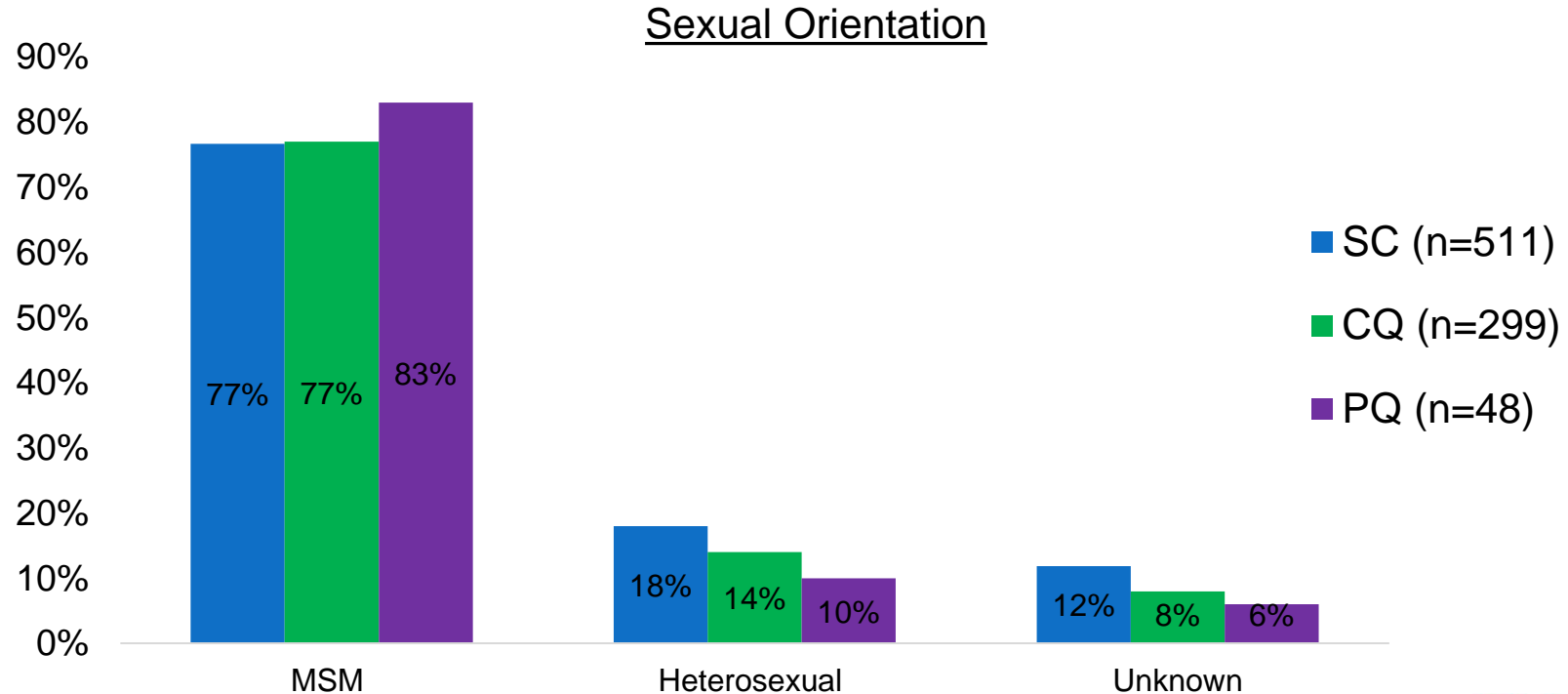
Ethnicity



Region of birth

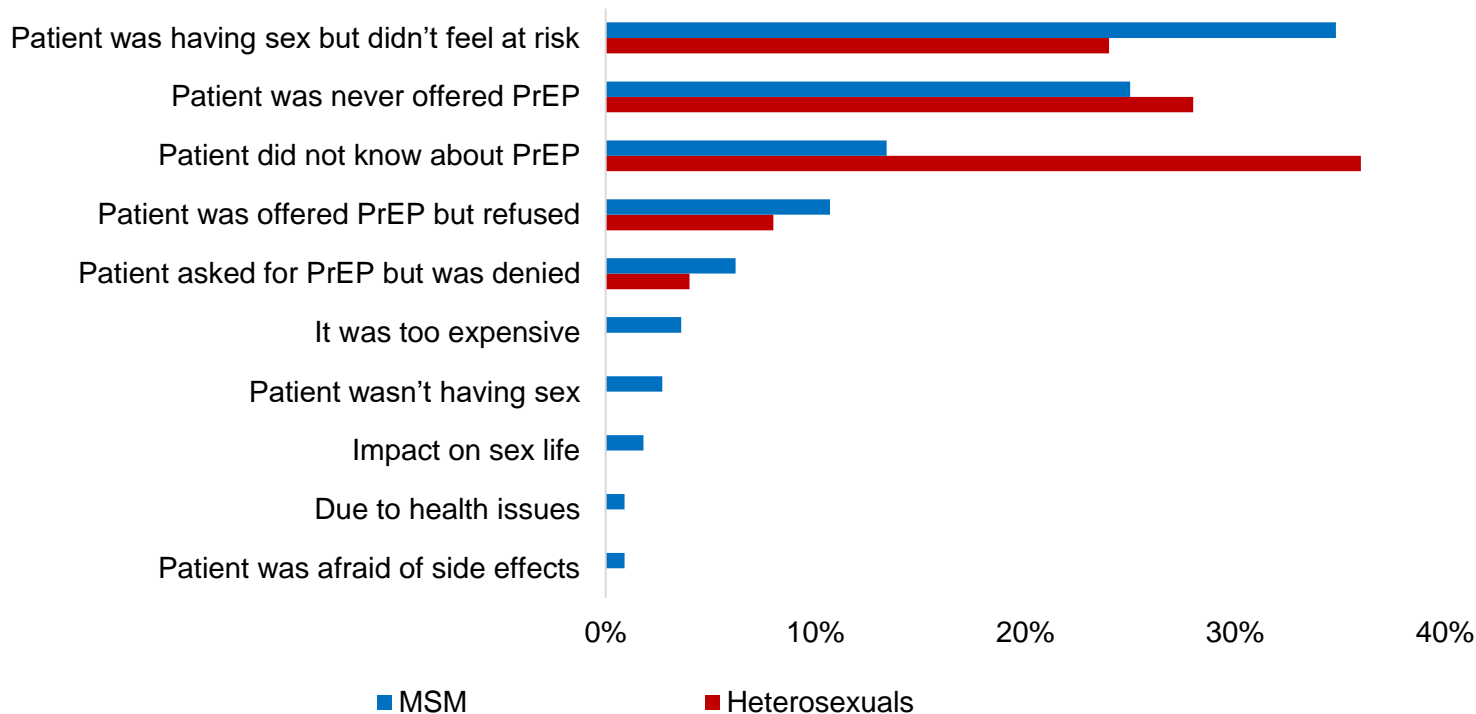


Comparison of demographics (1): all SCs, CQs, PQs

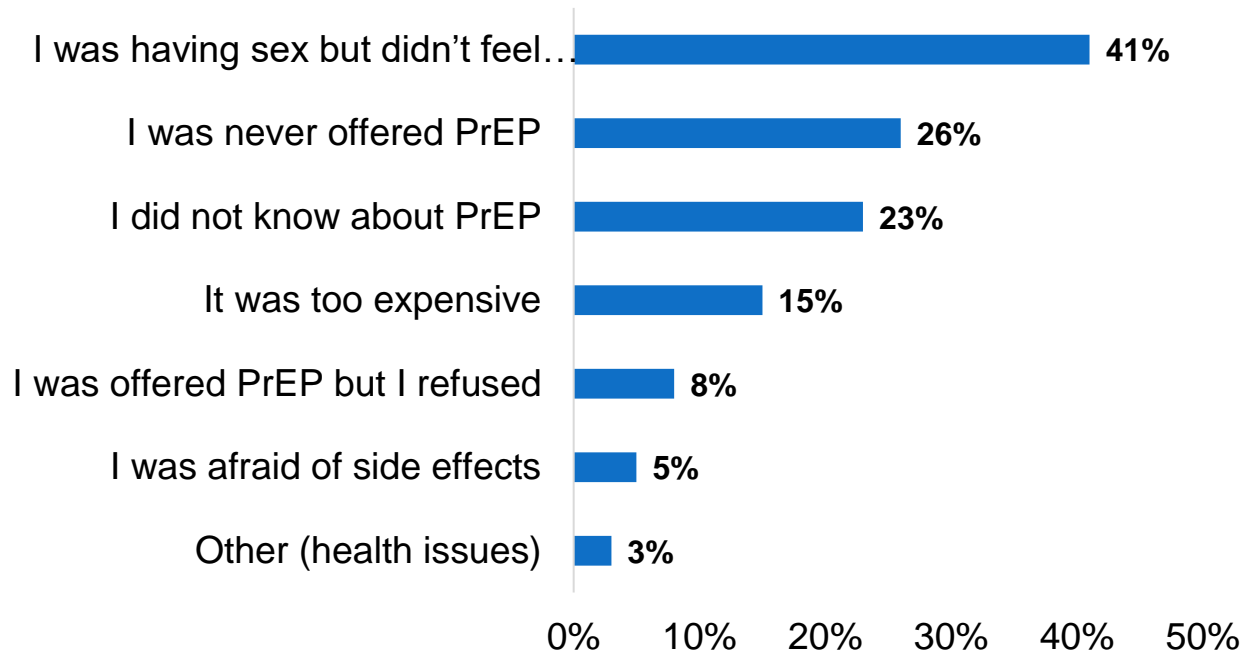


PrEP use history among SCs – Clinic Qs (n=299)

- **85%** (253/299) of SCs **had not used PrEP** (2018: 94%, 2019: 86%, 2020 75%)
- 86% (218/253) with no PrEP history indicated reasons for not taking PrEP



PrEP use history among SCs – PQ (n=48)



Sexual history prior to diagnosis –PQ (n=48)

60% had >2 condomless vaginal and/or anal sexual partners since their last HIV-test

Of the 16 people that reported having sex but not feeling at risk, approximately:

- *Around **one third** had had **>2 partners** since last HIV negative test*



Drug use prior to diagnosis - PQ (n=48)

45% had taken recreational drugs before or after sex*

Of people that reported '*having sex but not feeling at risk*' ~ **a quarter** reported drug use

Most common drugs were:

- Cannabis
- Ecstasy
- G, GHB, GBL
- Cocaine



*Note - very small sample



Additional comments why not on PrEP - PQ



Never offered

“Embarrassed about bringing it up”

“Didn’t have sex regularly enough”

Didn’t feel at risk

“Don’t like taking pills – long term”

“Monogamous relationship, felt safe”

“Am top- risk is much lower”

Didn’t know about PrEP

“Don’t like going to the doctors”

How do SCs think they acquired HIV (n=40)

Most associated a specific event with their exposure. These could broadly be grouped into:

- Casual sex, 1 night stand, transactional sex (n=19)
- Sex with a regular partner (n=9)
- Failed interventions (e.g. split condom, serosorting) (n=7)
- Oral sex (n=2)
- Don't know (n=3)

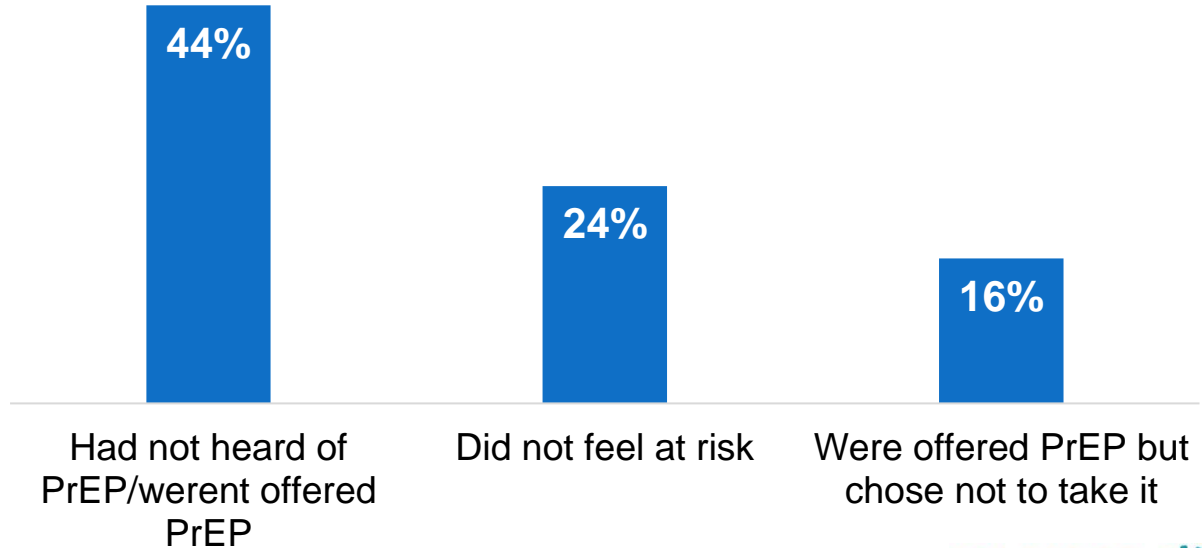
STI history & reasons for no PrEP – CQ (n=299)

57%

had a
bacterial STI
in the
previous year

Seroconverters with an STI in last year and reason
for no PrEP use (n=103)

50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%



What have we learnt from SHARE to date

- A large fraction of SCs had risk indicators e.g. STI in the last year
- Risk perception, knowledge and access were the main barriers for PrEP use in this population. Need better understanding of how risk perception relates to actual risk
- Value in using open-ended questions, highlights issues not captured in surveillance returns (e.g. stigma, fear)
- SCs identified in data systems are predominantly younger MSM, born in UK/EU. Few heterosexuals, likely due to differences in HIV testing patterns.
- Difficult to collect data directly from patients using this method

Changes to landscape affecting SHARE



- Routine PrEP commissioning, issues around access will change



- Roll out of GUMCAD v3 (includes sexual behaviour, alcohol and drug use, outcomes of PN)

Key areas to monitor going forward

- ✓ • Understanding knowledge, attitudes and awareness of HIV prevention options among SCs
- ✓ • Understanding reasons for stopping PrEP among SCs with PrEP use history
- ✓ • Understand potential barriers to HIV prevention options (among people not linked into SH services)

Key challenges

- Identifying SCs with no HIV testing history
- Obtaining more information on heterosexuals
- Timing of data collection (follow up with clinics, HARS delay 1-2 quarters)



Future of SHARE

- Modified questionnaire
- Clinicians only
- Online only

Other work:

- In-depth interviews among seroconverters of a range of backgrounds and risks.

Declaration of interests relating to this presentation

- Nothing to declare
- Thanks to all patients, healthcare staff and reporters for taking the time to be part of this initiative.
- Any feedback or comments please send to:
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