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# PrEP For Women – How far have we come and what still needs to be done

Sophie Strachan

CEO, Sophia Forum

Co-chair PrEP equity working group

# Conflict of Interest

In relation to this presentation I declare that I have no conflict of interest

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# PrEP conversations in 2016

- Initial HIV pre-exposure prophylaxis (PrEP) conversations revealed assumptions that women do not take risks
- HIV risk perception
- Gender based violence increases acquisition of HIV, yet the focus in early conversations was limited to solely that, which portrayed women as disempowered victims
- No information tailored to meet the needs of cis and trans women

# A human rights-based framework for prevention

- The Right to the highest attainable standard of health
- The right to be free from discrimination
- The right to benefit from scientific progress
- The right to education and information

# Addressing barriers to PrEP knowledge and access

- **Collaboration** between Sophia Forum and Ibase to develop tailored information to increase awareness and knowledge and benefits of PrEP for cis-gender and trans-gender women
- **Collaboration** with individuals and organisations both globally and local, we developed a website [www.womenandprep.org.uk](http://www.womenandprep.org.uk)
- **Continued Advocacy** for PrEP equity via PrEP Impact trial Women and other group and the new PrEP equity working group

# Sophia Forum statement 2016

## Prevention Principles

- No individual means of prevention should be considered in isolation, but as part of a comprehensive package of prevention
- Preference should be given to education/ programmes/ interventions that are: evidence-based; least burdensome; accessible to all; equitable to all; monitored for impact with data disaggregated by gender, sex, age and other factors.
- Any decision-making on access, availability and programmes should have meaningful involvement of all communities that might benefit (including women).
- [https://www.huffingtonpost.co.uk/jacquistevenson/nhs-england-decision-on-p\\_b\\_9617272.html](https://www.huffingtonpost.co.uk/jacquistevenson/nhs-england-decision-on-p_b_9617272.html)

# Collaborative work with I-base

<p><b>Getting started</b></p> <ul style="list-style-type: none"> <li>• Talk to a health advisor, doctor or nurse in your sexual health clinic.</li> <li>• You must test for HIV. Make sure it is a fourth-generation antigen/antibody test or a PCR.</li> <li>• You must test for hepatitis B. The drugs in PrEP are active against both HIV and hepatitis B.</li> </ul> <p>These tests are free in NHS sexual health clinics if you say you are using PrEP.</p> <p>✱ Testing for HIV and other STIs is recommended if you have sex with or without PrEP.</p>	<p><b>How to take PrEP</b></p> <ul style="list-style-type: none"> <li>• Take one pill a day for seven days <b>before</b> having sex.</li> <li>• Carry on taking it every day.</li> <li>• If you decide to stop PrEP it's important you take it for seven days after the last time you had sex.</li> </ul>  <p><b>Tip:</b> Use a pill box. This is a simple way to know if you have taken or missed your PrEP.</p> <p><b>Tip:</b> Pick the best time to take PrEP and get into a routine.</p> <p><b>Tip:</b> Set a repeat alarm on your phone or use an App.</p> <p><b>Tip:</b> If you forget to take a pill on time, take a dose as soon as you can. A late dose is better than no dose.</p>	<p><b>Keep taking PrEP for 7 sex-free days before you stop.</b></p> <p><b>Monitoring</b></p> <p>Regular HIV testing is essential when taking PrEP.</p> <p>Continue to test every 3 to 4 months for HIV and STIs.</p> <p>The sexual health clinic will take your bloods to do routine kidney monitoring (how often varies for different people).</p>	<p><b>Side effects of PrEP</b></p> <p>Most people don't get side effects. For those who do they are usually mild and stop within a few days. Routine monitoring will check for more serious but rare reactions.</p>  <p>Drug resistance to PrEP is very low. This guide is useful for more information on resistance and side effects: <a href="http://www.i-base.info/guides/prep.pdf">www.i-base.info/guides/prep.pdf</a></p>	<p><b>PrEP can help you enjoy sex without worrying about HIV</b></p>	<p><b>Information</b></p> <p><a href="http://www.womenandprep.org.uk">www.womenandprep.org.uk</a>  <a href="http://www.i-base.info/prep-for-women">www.i-base.info/prep-for-women</a>  <a href="http://www.prepster.info/prep4women">www.prepster.info/prep4women</a>  <a href="http://www.iwantprepnow.co.uk">www.iwantprepnow.co.uk</a>  <a href="http://www.bhiva.org/PrEP-guidelines">www.bhiva.org/PrEP-guidelines</a></p> <p>For free printed copies of this leaflet email Sophia Forum at <a href="mailto:info@sophiaforum.net">info@sophiaforum.net</a> or order online (including the 24-page booklet 'UK Guide to PrEP') at: <a href="https://i-base.info/forms/order.php">https://i-base.info/forms/order.php</a></p> <p><b>Sophia I-base</b>  <a href="http://www.sophiaforum.net">www.sophiaforum.net</a></p> <p><small>Take away 2 022   100% of all test results shared confidentially</small></p>	<p><b>PrEP for women</b></p>  <p>ONE PILL ONCE A DAY PROTECTS AGAINST HIV</p>
<p>This information is for people who identify as cis women, transgender or non-binary and have sex with men.</p> <p>HIV is a sexually transmitted infection (STI). PrEP can protect us from HIV even if we don't use condoms.</p> <p>PrEP is a pill that contains two HIV drugs: tenofovir (TD) and emtricitabine (FTC).</p> <p><b>PrEP works!</b></p>	<p><b>Is PrEP right for me?</b></p> <p>PrEP works whatever your gender, sexuality or ethnicity.</p>  <p>But, first make sure you have all the information you need to make a decision about PrEP. Read more here: <a href="http://www.womenandprep.org.uk">www.womenandprep.org.uk</a></p>	<p><b>Trans women and PrEP</b></p> <p>PrEP protects trans women:</p> <ul style="list-style-type: none"> <li>• who have receptive vaginal, frontal (front hole) or anal sex</li> <li>• who are the insertive partner in sex (top)</li> <li>• whether or not you have had lower surgery.</li> </ul> <p>Dosing choices depend on the type of sex, but generally daily dosing is recommended.</p> <p>Contact these services for the trans and non-binary community:  <a href="http://www.clinic.org.uk/prep-prep">www.clinic.org.uk/prep-prep</a>  <a href="http://www.dean.su/trans-non-binary">www.dean.su/trans-non-binary</a></p>	<p><b>PrEP and hormones</b></p> <p>PrEP is very safe when taking gender-affirming hormones and for cis women taking HRT for the menopause.</p> <p>PrEP is safe to use with all hormonal contraception (ring, patch, the pill or an implant).</p> 	<p><b>PrEP and pregnancy</b></p> <p>If you are planning a pregnancy or not using contraception, daily PrEP can protect against HIV.</p> <p>However, if you fall pregnant please tell your doctor. If you are still at risk of HIV, guidelines recommend continuing PrEP.</p> <p>Daily PrEP is very safe if you chest/breastfeed. The low levels of drugs in breast milk are not harmful.</p> <p>Check out: <a href="http://www.womenandprep.org.uk">www.womenandprep.org.uk</a>          Use this tool to check if PrEP interacts with any other meds you are taking: <a href="http://www.hiv-druginteractions.org/checker">www.hiv-druginteractions.org/checker</a></p>	<p><b>Sex work</b></p> <p>PrEP can be used when working in the sex industry, including porn. Many sex workers look after their sexual health but their clients might not.</p> <p>PrEP will protect against HIV if you are pressurised to not use condoms.</p> <p>Specialised sexual health services (free from stigma and judgement) are available and recommended.</p> <p>Join the community of sex workers: <a href="http://www.uglymugs.org">www.uglymugs.org</a></p> 	<p><b>Getting PrEP in the UK</b></p> <p>PrEP is available free from NHS sexual health clinics in England, Scotland, Wales and Northern Ireland.</p> <p>In the future there will be more places to access PrEP, like your GP and local pharmacies.</p> 



# Collaboration International and local

A woman with long brown hair, wearing a black coat over a yellow sweater, walks on a wet city sidewalk. She holds a brown umbrella in her left hand and a white coffee cup in her right. The background shows a rainy street with buildings and a sign that says 'Food & Drinks Takeaway Only'.

Women and PrEP   About Us   PrEP   PrEP in the UK   HIV

## #PrEP4Every1

## #1pilladay

Have you heard of PrEP?

It's a safe, daily pill that prevents you from getting HIV.

Find out all you need to know about PrEP to help you decide if it's right for you.



# PrEP IMPACT Trial 2017

- Recruited 24,255 high risk individuals over 3 years.
- Women and other community subgroup formed
- A community of activists and organisations working with PrEP IMPACT Trial, oversight group and community advisory board and research team
- (Spectra, Africa Advocacy Foundation, CliniQ, Sophia Forum, Juddy Otti, Porn4PrEP, Del Campbell (National Ugly Mugs), Kate Nambiar)

## Results

Recruitment period 13<sup>th</sup> October 2017 - 12<sup>th</sup> July 2020

157 Sexual Health Services across all English regions

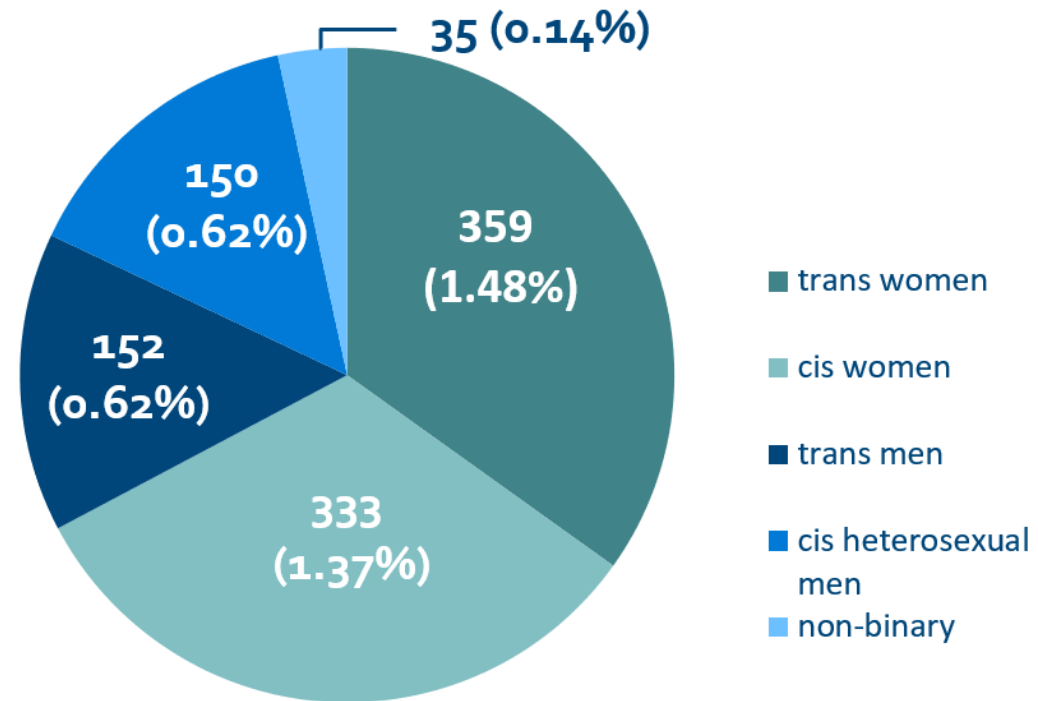
Total participants	24,255 individuals	
MSM	23,217	95.7%
Other groups	1038	4.3%

Daily regimen was initially chosen by 85% MSM

PrEP Impact Trial

Sullivan et al BHIVABASHH 2021

## Participants from groups other than cisMSM



PrEP Impact Trial

Sullivan et al BHIVABASHH 2021

# BHIVA-BASHH PrEP Guidelines

Recommend PrEP	
<p>(i) HIV-negative MSM and trans women who report condomless anal sex in the previous 6 months and on-going condomless anal sex. (1A)</p> <p>(ii) HIV-negative individuals having condomless sex with partners who are HIV positive, unless the partner has been on ART for at least 6 months and their plasma viral load is &lt;200 copies/mL. (1A)</p>	
Consider PrEP on a case-by-case basis	
PrEP may be offered on a case-by-case basis to HIV-negative individuals considered at increased risk of HIV acquisition through a <b>combination of factors</b> that may include the following:	
<b>Population-level indicators</b> <ul style="list-style-type: none"> <li>• Heterosexual black African men and women</li> <li>• Recent migrants to the UK</li> <li>• Transgender women</li> <li>• People who inject drugs</li> <li>• People who report sex work or transactional sex</li> </ul>	<b>Clinical indicators</b> <ul style="list-style-type: none"> <li>• Rectal bacterial STI in the previous year</li> <li>• Bacterial STI or HCV in the previous year</li> <li>• Post-exposure prophylaxis following sexual exposure (PEPSE) in the previous year; particularly where repeated courses have been used</li> </ul>
<b>Sexual behaviour/sexual-network indicators</b> <ul style="list-style-type: none"> <li>• High-risk sexual behaviour: reporting condomless sex with partners of unknown HIV status, and particularly where this is condomless anal sex or with multiple partners</li> <li>• Condomless sex with partners from a population group or country with high HIV prevalence (see UNAID definitions [1])</li> <li>• Condomless sex with sexual partners who may fit the criteria of 'high risk of HIV' detailed above</li> <li>• Engages in chemsex or group sex</li> <li>• Reports anticipated future high-risk sexual behaviour</li> <li>• Condomless vaginal sex should only be considered high risk where other contextual factors or vulnerabilities are present</li> </ul>	<b>Drug use</b> <ul style="list-style-type: none"> <li>• Sharing injecting equipment</li> <li>• Injecting in an unsafe setting</li> <li>• No access to needle and syringe programmes or opioid substitution therapy</li> </ul> <b>Sexual health autonomy</b> <p>Other factors that <i>may</i> affect sexual health autonomy</p> <ul style="list-style-type: none"> <li>• Inability to negotiate and/or use condoms (or employ other HIV prevention methods) with sexual partners</li> <li>• Coercive and/or violent power dynamics in relationships (e.g. intimate partner/domestic violence)</li> <li>• Precarious housing or homelessness, and/or other factors that may affect material circumstances</li> <li>• Risk of sexual exploitation and trafficking</li> </ul>

## Distributing a questionnaire for women attending a Sexual Health Clinic increases PrEP uptake

S. Strachan , S. Jaffer , V. Apea , D. Campbell , J. Domino , L. Davies , J. Dugdale , K. Nambier , D. Onyago , J. Otti , M. Ross , J. Stevenson, N. Turner, G. Singh, A. Sullivan

### Introduction

- The PrEP Impact trial was established in 2017 to assess the need for PrEP in English Sexual Health Clinics. Early recruitment data demonstrated significant under-representation of women (<5%).
- The use of pre-exposure prophylaxis (PrEP) is a safe and effective prevention option to all people at substantial risk of HIV acquisition, irrespective of gender.
- Barriers to women's PrEP uptake include lack of awareness, lack of offer, gender bias and low HIV risk perception at both clinician and individual level.

### Methods

- A questionnaire, based on the National PrEP guidelines, was developed to assess potential factors associated with increased risk and was given to women attending one sexual health clinic between 09/01/2020 and 19/03/2020.
- It consisted of 30 questions, including both polar questions and free text answers.
- The clinician recorded outcomes for PrEP discussion, PrEP eligibility and whether referred to the PrEP Impact Trial or opted for an alternative source.
- We aimed to assess the effectiveness of the questionnaire in identifying women who might benefit from PrEP.



### Results

- A total of 624 questionnaires were completed; 573 (91.7%) by cis women.
- The median age was 25 years (range 14-55) and the majority were of white ethnicity (64.2%).

Sexual behavior and risk factors	n (%) 21 (100%)
'Sometimes does not use condoms'	19 (90.5)
Sex with a person of unknown HIV status	9 (42.9)
Sex under the influence of drugs/alcohol	9 (42.9)
Has been asked to send naked/sexual images	9 (42.9)
Coerced into sex	5 (23.8)
Snorted drugs	6 (28.6)

- During the two months 21 women (6.6%) were identified as being PrEP eligible; of whom 15 (71.4%) then had a conversation about PrEP documented; 8 (38.1%) accessed PrEP via the trial (6 cis, 2 trans; 6 White, 2 Asian); 1 (4.8%) self-sourced PrEP privately and 1 (4.8%) declined to participate in the trial.
- During the preceding 26 months of the PrEP Impact trial 10 women had been recruited at the clinic.

### Conclusion

- Our data demonstrates a simple intervention was effective in initiating discussions about and increasing uptake of PrEP by women attending a Sexual Health Clinic.
- More work is required to develop a brief intervention tool to aid these conversations taking place during routine Sexual Health Clinic Attendances.



# Underserved population – Homeless people

- Homelessness and health
- Approximately 250,000 people homeless in the UK
- Two thirds are based in London
- Homelessness and HIV
- Prevalence of HIV is eight times higher amongst people experiencing homelessness than the general population. 3.2% compared to 0.4%
- During COVID19 pandemic people experiencing homelessness were temporarily housed in hotels and BBV testing was undertaken at some sites



# Prevention interventions

- Of 1108 tested 35 tested positive for HIV, 17% new diagnoses
- For those already diagnosed 23% were not engaged in care, and those who had started ART 20% had recent interruption to regime.
- Among the cohort of homeless people temporarily housed during COVID19 45% had never had an HIV test
- Additional analysis of this dataset identified 2/1103 people experiencing homelessness were using PrEP despite a high prevalence risk factors for HIV Acquisition (Sultan,B personal communication)

# Barriers to uptake of PrEP

- Lack of awareness
- Gender bias
- Lack of offer
- Low HIV risk perception of risk at clinician and individual
- Access via sexual health clinics only is a barrier for underserved populations, integration into other services and diversifying access points is key, especially for homeless population and people who inject drugs

# Conclusions

- Risk assessment for women is much more complex than for MSM for whom clear indicators of HIV acquisition exist (rectal STI, syphilis, presentations for PEP and condom less anal sex)
- When discussing HIV risk with women, it is likely that framing this in the context of overall sexual and reproductive well-being will be a more effective strategy than in terms of HIV risk alone
- Crucial to create an atmosphere of compassion and trust to ensure that conversations yield information that will lead to effective outcomes
- Language should be tailored specifically to particular women/communities to ensure that messages are correctly understood. This can only be achieved by directly engaging with individuals and communities
- A need for PrEP champions to promote and deliver on-going care in all healthcare settings and community spaces
- Continued commitment and long-term financial investment in collaborative prevention projects if we are going to meet targets of zero HIV infection by 2030

# PrEP Awareness Videos

Below are a suite of *community-led and community co-designed* PrEP awareness videos.

Please watch and share!

#PrEP4Every1



PrEP Awareness Video - Main Montage



PrEP Awareness Video - Non-binary & Trans - Akiko



PrEP Awareness Video - Sex Workers

# Our Strategy Ensuring PrEP for ALL

PrEP IMPACT TRIAL: COMMUNITY ADVISORY BOARD  
WOMEN AND OTHER GROUPS SUBGROUP  
STRATEGY 2021: ENSURING PrEP FOR ALL

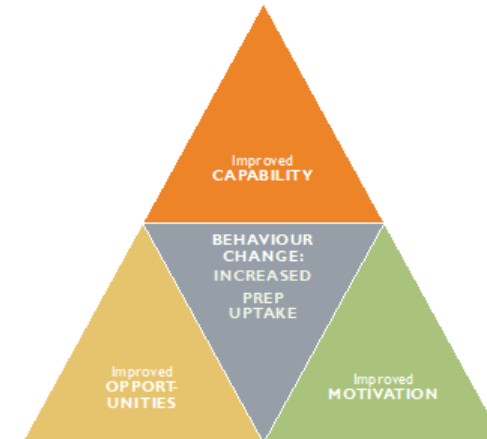
■ **VISION:** Equity in PrEP awareness, access and provision across **ALL** groups at risk of acquiring HIV

■ **KEY OBJECTIVES:**

- Promote **PrEP literacy** amongst women and other groups at risk of HIV
- Promote **PrEP candidacy** amongst women and other groups at risk of HIV
- Increase **PrEP uptake** amongst women and other groups at risk of HIV

■ **UNDERPINNING FRAMEWORK:**

- Our strategy is anchored by three key strands (**Education, Advocacy and Research**), informed by the **COM-B framework** of behaviour change.
- COM-B posits that there are three types of influences upon behaviour:
  - **‘Capability’** (knowledge and skills)
    - *Knowledge and/or experience with PrEP*
  - **‘Opportunity’** (structural and environmental factors)
    - *Barriers and facilitators for providing PrEP*
  - **‘Motivation’** (attitudes, habits, decision-making)
    - *General attitudes and opinions on PrEP*
- Our proposed strands of work intend to enhance capabilities and opportunities and positively influence the motivation for PrEP amongst potential PrEP users



# Our Strategy Ensuring PrEP for ALL

*There is an urgent need to develop and implement evidence-based interventions to increase prep candidacy and uptake amongst women and other groups at risk for HIV infection.*

*People need access to competent, affirming, sex-positive, safer-sex information that is specifically geared toward their bodies, relationships, and community concern.*

## ■ EDUCATION:

### ■ Communication to change the narrative of PrEP

- Redefining the perception of risk and vulnerability
- To be targeted at potential PrEP users and PrEP providers to ensure they appropriately identify those at risk

### ■ Communication to disseminate the work of the subgroup

- Policy statement
- Enhance social media profile of sub-group by independent social media accounts or via aligned organisations

### ■ PrEP demand creation and conversation

- Via Videos
- Via posters
- Via podcasts, Facebook live and TED talks



## ■ ADVOCACY:

### ■ Develop defining policy statement

- Lobby commissioners, Public Health England and other stakeholders outside of the HIV and Sexual Health sector

## ■ RESEARCH:

- Identify and reflect on **what we know already** about PrEP and women and other groups

- Identify **barriers to PrEP** that are specific to different groups

- Identify solutions or responses to these specific barriers

- **Desk top review** of community initiatives / community and research data in Europe around women and other groups' knowledge and access to PrEP

- Mapping /scoping/analysing

- Identify the themes and gaps in research related to women and other groups

- **Rollout of Women and PrEP questionnaire**

- Qualitative sub-study – One 2 one interviews and focus group discussions



# Thank you

[sophie.strachan@sophiaforum.net](mailto:sophie.strachan@sophiaforum.net)

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