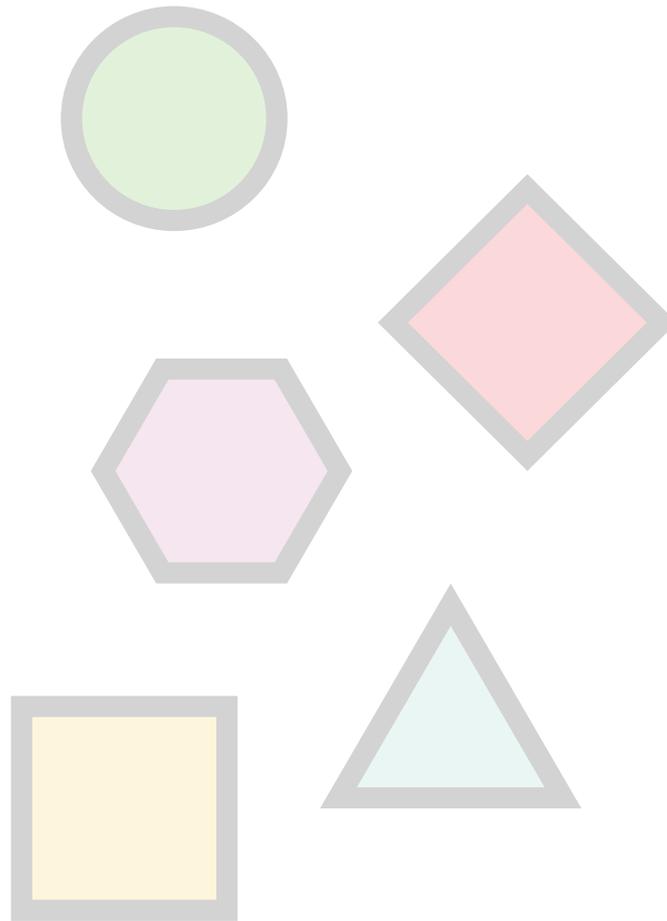


PrEP and Women in Scotland Roundtable: A Community Report

17 September 2018, Glasgow

Hosted by:
Developing HIV Literacy
PrEPster
HIV Scotland



This event took place at Glasgow Caledonian University.

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Aims

Pre-exposure prophylaxis (PrEP) has been available in Scotland since July 2017. However, very few people currently accessing PrEP are women. While there has been considerable discussion around the need to expand PrEP awareness, access and use to women, there have been very few coordinated discussions which: recognize the diversity of women; explore the needs of all women in relation to PrEP and plan out PrEP pathways that are accessible and acceptable to women.

The aims of this roundtable, organised by Developing HIV Literacy, PrEPster and HIV Scotland, were to:

- **identify and reflect on what we know already about PrEP & women in Scotland;**
- **identify which women we are talking about and ensure that our discussions reflect this;**
- **identify barriers to PrEP that are specific to diverse groups of women;**
- **begin to identify solutions or responses to these specific barriers.**

Research overview

The roundtable began with three brief presentations on research done on and around PrEP and women in Scotland. The presentations were then followed by discussion about related research and concerns.

Ingrid Young (University of Edinburgh) provided an overview of key findings from qualitative research with **African women living in Scotland** as part of *HIV & the Biomedical* research project (2012 - 2014). Participants included women who were HIV-negative and were living with HIV from across Glasgow, Lothian and Grampian. Key issues to emerge from this work included:

PrEP Candidacy & HIV risk perception

- Most participants did not see themselves as PrEP users.
- For many the condom worked well or they did not feel they were at risk of HIV acquisition.

Concerns that PrEP could interfere with existing strategies

- PrEP could offset condom use & other strategies that are not specific to HIV risk reduction (e.g. STIs, pregnancy).

HIV stigma & social risks

- Concerns expressed by some that PrEP may be mistaken for HIV *treatment* & this could lead to being *mistakenly* identified as someone living with HIV.
- Potentially negative implications of PrEP use and disclosure (intentional/unintentional) to sexual partners.

(Mis) Trust & control

- Concerns by participants living with HIV around potential for incorrect use by partners & their own lack of control of the prevention method.
- Concerns that PrEP was an unreliable option.

(Mis) Trust around TasP & undetectable viral loads

- Relatedly, undetectable viral loads (currently something that would deem a partner ineligible for PrEP in Scotland) were also *not* trusted as reliable prevention strategies.

Sarah Nakasone (University of Chicago) provided an overview from her recent research on PrEP and sexual health with **Black, Asian and Minority Ethnic (BAME) women in Glasgow**. This work was part of a larger project with a total of 32 women from BAME communities across London and Glasgow. After preliminary analysis, key issues to emerge from the research included:

- a need to address institutional racism and bias against people living with HIV within and across health services;
- awareness of PrEP remains low but interest, once introduced, is high and finding opinion/peer leaders will likely not be difficult;
- the UK's pattern of refugee resettlement fragments migrant communities, limiting the opportunities for peer support;
- age may play an important role in social patterns of safer sex and fear of HIV - younger women (in London) expressed different attitudes to risk of HIV and safer sex practices to their older counterparts.

Matt Smith (Glasgow Caledonian University) presented preliminary findings with interviews he conducted in Glasgow with **people who use drugs** and with outreach workers. Interviews with people who use drugs were predominantly with people attending services for stopping injecting drug use. There was overall enthusiasm for PrEP, especially in the context of opioid replacement therapy (ORT). Key findings from preliminary analysis included:

- PrEP provision could take place through pharmacies with existing infrastructure, although concerns were expressed around the limitations of the distribution of generic medications;
- concerns that harm reduction practices around sexual transmission of HIV and transmission via drug use did not overlap - this was especially highlighted in the context of concurrent sexual partners and limited condom use.
- women specific findings related largely to sex work practices and related stigmas.

Follow up discussion explored overlaps between people using drugs and **sex work**, especially through research **Anastacia Ryan** (Umbrella Lane) conducted around sex work. Key points:

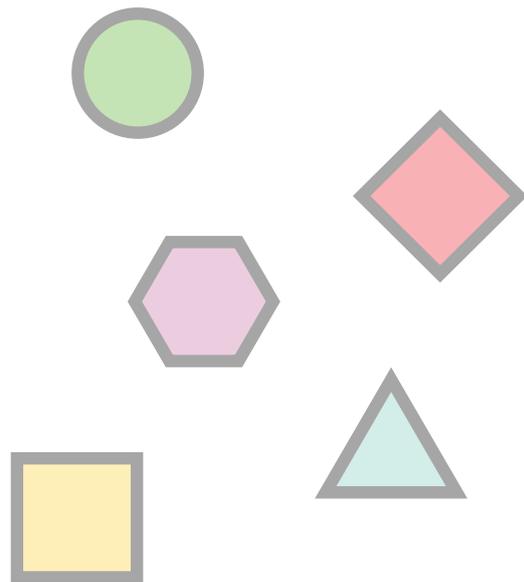
- **Stigmatising and othering processes within already highly stigmatised groups** (such as people who use drugs) **can be experienced by women** in particular through attitudes towards sex work or transactional sex.
- **Increased policing and criminalization of sex work in Scotland shapes women's agency and autonomy to negotiate sex work and sex more generally.** This raises issues around distinguishing between sex work and other forms of transactional sex (and if women using drugs had the autonomy to 'choose'). Clarity is needed on what can and should be called sex work within this context. It also raises issues around how PrEP could be used as corroborating evidence in the same way that condoms are currently used as evidence for sex work and naloxone is used as evidence of drug use.
- **Cautions were raised about delivering PrEP in combination with ORT (or indeed, a requirement to exit sex work) and the risk of potential coercion** where one is made - or perceived to be - a pre-requisite to access the other. It was noted this was already perceived to be the case in relation to HIV treatment amongst some people who use drugs who were living with HIV. It was agreed that PrEP should not be provided through organisations who advocate abstinence only approaches (eg. exiting sex work, mandatory ORT) as opposed to harm reduction approaches.
- Increased policing had been observed within Glasgow and participants aired concerns about how agencies (police, health, etc) may or may not be sharing information about vulnerable populations when accessing services. It was also noted that **fears and experiences of increased policing extended to other communities, such as asylum seekers, which diminishes trust in the safety of services.**

General problems

Participants had been asked to come to the roundtable having thought about the key problems for PrEP and women. We then had a general discussion of problems facing the awareness, provision, access and use of PrEP amongst women in Scotland.

Key issues to emerge included:

- lack of awareness of PrEP;
- uncertainty around candidacy and/or eligibility on the part of both potential PrEP users and community workers who might provide advice/support;
- poor, non-inclusive or exclusionary language in PrEP material or information;
- limited or no knowledge of PrEP in health services outside of GUM or sexual health services, which are more likely to be used by women;
- limited or restricted access to sexual health services (e.g. waiting times to make an appointment, get an appointment, etc) in Glasgow (and in other boards);
- lack of appropriate or targeted services for key groups as only gay/MSM (men who have sex with men) services currently available (e.g. trans specific sexual health services);
- avoiding NHS/health services due to discrimination, racism, exclusionary practices;
- limited or poor risk perception in relation to HIV.

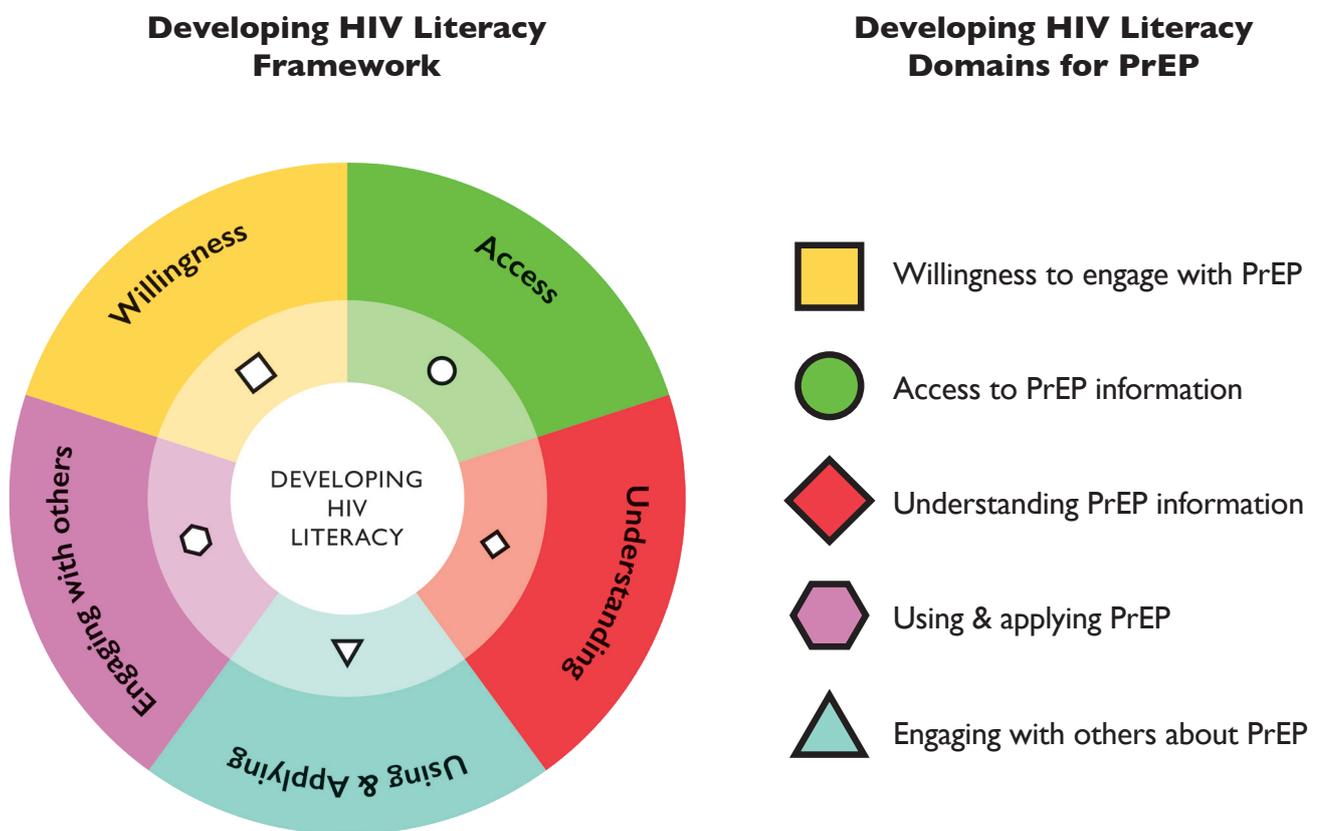


Identifying, describing and responding to diversity in women

Participants were asked to discuss PrEP issues & potential solutions as they related to specific groups of women. We discussed four specific but potentially overlapping groups:

- Black, Asian and Minority Ethnic (BAME) women**
- Women who sell sex**
- Women who use drugs**
- Trans women and trans people more broadly**

The following pages reflect in-depth discussion from small groups around problems for these specific groups of women, as well as some solutions.



HIV literacy is a complex process that is much more than about understanding HIV-related information. Drawing on the Developing HIV Literacy Framework (Young et al, forthcoming 2019), we have organised discussions into 5 domains to better understand at what point these problems - and solutions - may be best addressed.

Problems

Solutions

Willingness to engage with PrEP

HIV stigma limits conversations around HIV and PrEP use, and also can affect clinic attendance

Separating PrEP & HIV from wider sexual and reproductive health issues in material can make PrEP & HIV seem less relevant

Language used in eligibility criteria and wider PrEP material can be off-putting and not culturally sensitive

- e.g. high bacterial STI rates may be language used amongst some communities but not recognised in or as about BME communities
- words like rectum may be rejected (& indicative of stigma around anal sex)

Mixed messages from 'double culture'

- sex education in school (where delivered) can conflict with messages at home about 'abstinence'
- mixed age groups (e.g. under 30 & over 40) can create/exacerbate an imbalanced power dynamic - young women may engage in a different way with PrEP/HIV/sexual health but not be open or admit to this when in the presence of their 'elders'

Being 'high risk' is off putting and not a useful criteria for PrEP

- there is a need to understand what risk is and how risk applies to BAME women
- women may be at risk or vulnerable to HIV but do not see this or understand this
- concurrency of sexual partners may be a real factor that increases risk but is not acknowledged or discussed - a woman may know of her male partner's relationships with other women but will not raise this or end the relationships & may be at increased risk of HIV

Identify key points where PrEP and HIV discussions might become immediately relevant

- e.g. have discussions about HIV prevention with young women before holidays, especially 'back home' where they will need to deal with specific and different risks to a UK context

Identify how services can target, tailor or even be open to BAME women so they engage

- produce materials in a range of languages
- use culturally specific and relevant language & examples

BAME women & PrEP

Problems

Solutions

Access to PrEP information

Institutional racism within the NHS is a major barrier to engaging with health systems & health providers

There are no specific services for BAME women but targeting can be problematic

- lack of targeted services currently available
- but targeting can be done badly:
 - it has and can create hostility to being targeted and tested frequently
 - being treated as a 'vector of disease' creates further stigma and exacerbates racist stereotypes
- internalized/institutional racism within organisations is rarely acknowledged or addressed which directly affects if and how targeting/tailoring is done
- lack of multi-lingual materials is a barrier where women speak English as a second language (e.g. Swahili, Zulu)

PrEP specific workshops or information may not be appealing, but may be acceptable if via through more general sexual & reproductive health discussions

Create spaces where women can talk about PrEP, but provide guidelines about:

- who can come along
- who is encouraged &
- who can champion PrEP in their community

Use peer educations on PrEP

- recruit people who have appropriate cultural understanding but a neutral approach
- consider recruiting people who migrated to the UK pre-adolescence

Peer education programmes must pay attention to:

- cultural knowledge & positioning of the educators and peers with whom they will be working
- young women who have come to the UK pre-adolescence may not be seen to have adequate understanding of specific cultures and may not be regarded as knowledgeable or trustworthy
- recruiting women of reproductive age as peer educators may hold more (or different) currency amongst some groups

Create alternative pathways to access PrEP as BAME women may avoid GUM clinics

Engaging with others about PrEP

Women taking PrEP may not want to admit this to their peers, as they may fear accusations of having 'loose morals'

Women who engage in sex work & PrEP

Problems

Solutions

Willingness to engage with PrEP

Limited awareness & understanding of PrEP

Access to PrEP information

Policy & legislation issues

- criminalisation of sex work & increased policing/raids create hostile environment with state-funded services
- record and/or data sharing within and across NHS & 'obligation' in some cases to share information with social services, police & other agencies may create fear of disclosure for parents or those with precarious immigration status

Attitudes/approaches to sex work within NHS

- NHS staff views that sex work is always inherently violence against women feed into prejudice amongst health workers and hesitancy to disclose sex work
- lack of understanding or training for NHS staff with peers or people with lived experience of sex work
- concerns about lack of confidentiality & stigmatising by NHS practitioners

Concerns NHS does not trust peer led groups (for testing, health promotion, support) where different kinds of knowledge and experience are not recognized

Sandyford service is currently only for 'vulnerable people' which is not (always) appropriate for sex workers
Sex workers don't identify, and don't want to access services in this way

More training for peer-led organisations on PrEP and PrEP side effects

Services need to use language that is acceptable to sex workers themselves, including:

- referring to clients not punters, to services not sex acts
- not asking how much people are paid

Identify trusted clinicians who are good at supporting sex workers

- consider a pilot programme for sex workers within sexual health services

Need for confidentiality

- sexual health records not linked, using assumed names, issues around reliable contact forms
- train health workers to understand how vital this confidentiality is, especially in relation to criminalisation and/or being outed as a sex worker

Run sexual health services in partnership with other services which would create incentive to attend, avoid stigma, etc

- if clinic not run exclusively by sex workers, you can deny sex work (plausible deniability)
- running service alongside a drop in service with peers might be encouraging/good space to discuss the possibility of PrEP

Defining risk and vulnerability

- what is 'vulnerability' in relation to HIV - consider wider structures within which people work, such as criminalisation, coercion, coercive managers
- need to consider how sex workers may be more vulnerable/at risk of HIV transmission than other groups who do not face some of these more structural risk factors

Trans women/people & PrEP

Problems

Solutions

Willingness to engage with PrEP

Current PrEP material (eligibility criteria, leaflets, etc) does not use *inclusive language* & does not indicate that PrEP might be for trans people through this exclusion

- trans women are women but may not have a vagina or vaginal intercourse - material talks exclusively of anal or vaginal sex
- exclusion of non-binary people by not mentioning them
- risk criteria/material focuses on gender/sexuality, not sexual activity - this may be appropriate for the wider population but trans specific needs need to be considered

Use more inclusive and trans-specific language & be clear about/define what we mean

- define what is meant by men and women within material/criteria
- be explicit about trans inclusion within mainstream male and female but also have (and link to) trans exclusive or gender exclusive material that talks about activities and not gender

Being explicitly trans inclusive in language

- use 'all women' or 'all men'
- additional signposting in material e.g. 'we appreciate not all women have the same bodies'

Access to PrEP information

Significant barriers to accessing sexual health services where more specific PrEP information, support and access is available because they are not seen as 'trans aware or inclusive'

- people turned away from services because they do not have the correct genitalia (e.g. trans men at MSM clinics)
- lack of clarity about which women PrEP services are providing services for (e.g. what do they mean by women/men?)
- trans women do not want to access MSM services

Increased self-management of health care generally by trans people - how would PrEP fit into this?

- trans people missing out on lots of checks (e.g. breast/cervical screening, prostate screening)
- avoidance of many GPs until absolute emergency
- current NHS systems do not or cannot specify trans people

Need for reliable statistics of who or where trans people are to help targeting/tailoring

Questions around sex should be based on activity and equipment

Trans specific education for health practitioners

- sexual health practitioners
- primary care practitioners

Need for trans specific sexual health & PrEP services

- however; this may not work for some trans people - binary trans people who identify strongly with female/male won't access a trans service

Understanding PrEP information

Lack of trans specific PrEP information

- limited information about potential interaction of PrEP with hormone therapies
- concerns about how PrEP may interact with certain tissues, especially relevant in relation to surgery; currently little to no information on this

Provision of trans specific information around PrEP & interactions

Using & Applying PrEP

The group felt that there were no specific issues to raise around using & applying if other areas can be addressed

Women who use drugs & PrEP

Problems

Solutions

Willingness to engage with PrEP

Lack of awareness & knowledge amongst people who use drugs AND providers in addiction services about PrEP

- sexual transmission of HIV not seen or considered a risk; 'not for us' attitudes

Engage with how people define their risk of HIV & adjust self-assessments to match this

Need to change framework of PrEP (language, material, policy, etc)

- people need to see it is for them and not something they have been told is for them (e.g. top down)

Need for clarity around who can access PrEP/ who PrEP is for

- someone in authority to say PrEP is for *anyone* at high risk of HIV, made available in literature to ensure that knowledge & support is inclusive & trusted

Access to PrEP information

Criminalisation & increased policing as a major barrier to accessing PrEP specific support

- engaging with PrEP services might affect how they are engaging with other services & policy

Concerns about nature of support currently available for people who use drugs & their need to demonstrate commitment to access services

- e.g. motivation diaries to be completed before accessing treatment

Concerns round moralizing & politics (e.g. abstinence approach instead of harm reduction) that contributes to guideline development for drug users

Licensing only for sexual transmission of HIV rather than transmission through drug use could complicate access if environment of services are not open to harm-reduction oriented sexual health approaches

Inability to access sexual health services in Glasgow

- individual issues with travel to clinic, perceived unfriendliness of service to people who use drugs
- limited to no access to appointments at present (27min waiting time on phone; significant wait for appointments)

Access to PrEP information, support & services needs to move away from existing services (e.g. central sexual health clinics)

Clear pathways to PrEP to be signposted & first point of contact to be clarified

Translate HIV risk discourse from epidemiology to lived experience of people who use drugs

- support needed to help non-sexual health community workers identify potential eligibility for PrEP with the people they work with, without it being a clinical assessment
- similarly, consideration of negative impact on people (mental health, fear, anxiety, etc) when PrEP is requested but told they aren't eligible

Support for PrEP narratives to help navigate access

- support to help translate lived experience and real instances of high risk into language/narratives that more directly match eligibility criteria (akin to experiences of recounting stories in asylum seeking & navigating asylum system)
- clinical need vs narratives of risk

Services & policies need to adopt a harm reduction approach & address moralising tendencies in policy making and provision

Decentralising decision making & practice around prescribing

- what are the possibilities of alternative models of prescribing e.g. virtual supervisory clinics (Echo), conference calls, remote oversight

Women who use drugs & PrEP

Problems

Solutions

Using & Applying PrEP

Precarity in the lives of people who use drugs complicates PrEP use (access to PrEP, regular testing, adherence, etc)

- concerns around dropping out of routines & how this might affect PrEP use and other treatments

Next steps

These discussions reflect the *first steps* of collaborative discussions with community stakeholders in Scotland to think about women and PrEP.

We hope that these initial notes will:

- provide a useful resource for clinical and community practitioners to begin to think critically about women & PrEP;
- lead to more focused engagement with diverse communities of women to explore specific needs in relation to PrEP awareness and knowledge, and;
- help support creative and appropriate solutions to ensure equitable and appropriate awareness, access and use of PrEP for women.



Contact details

For more information on this report, or to get in touch if you would like to discuss PrEP access and use in Scotland and beyond, feel free to contact:

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