


# 'We go where we know': Reflections from Mobilizing for PrEP and Sexual Health (MobPrESH) – A peer-led PrEP education programme across England, for and by women and non-binary people

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## Abstract

**Background:** Pre-exposure prophylaxis is a highly effective method of HIV prevention but few women know about it, have access to it, or see it as relevant to them. In 2019, grassroots organization PrEPster piloted a peer-led intervention, MobPrESH (Mobilizing for Pre-Exposure prophylaxis (PrEP) and Sexual Health), across three sites in England, to mobilize for PrEP and sexual health with communities of women and non-binary people most affected by HIV, including Black women and non-binary people, people of colour, migrants, and transgender (trans) women.

**Objectives:** We aimed to explore the accessibility, feasibility, acceptability, and 'fidelity' of MobPrESH, from the perspectives of peer mobilizers and project staff.

**Methods:** We conducted focus group discussions and qualitative interviews with nine peer mobilizers (most identified as Black cisgender (cis) women) and six project staff (including Black and white cis women and non-binary people). We analysed data thematically, iteratively, and inductively, informed by concepts of reproductive and social justice.

**Results:** We present findings in five thematic areas: connecting and relating to situate sexual health discussions, navigating silence and stigma, connecting within and across communities, competing pressures and structural hostilities, and resources and continuity. Community knowledge-building about PrEP is a slow, iterative process that needs investment and creation of trusted spaces that centre communities' needs and concerns. Peer mobilizers and the communities they engaged with had competing demands in their lives, and knowledge-raising about PrEP was impacted by intersecting stigmas, discrimination, and oppressions around HIV status, racism, misogyny, transphobia, homophobia, and anti-sex worker rhetoric.

**Conclusions:** Peer-led PrEP interventions require funding and foregrounding, particularly for women and non-binary people who are Black, trans, migrants, and people of colour, situated relative to their wider health needs, life pressures, and priorities. This requires concurrent challenge of the racist and patriarchal structures that continue to obscure the sexual and reproductive health needs of racially minoritized and marginalized women and non-binary people.

## Keywords

HIV, peer-led programmes, PrEP, qualitative research, sexual and reproductive-health and justice, women

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## Introduction

Pre-exposure prophylaxis (PrEP) is a highly effective method of HIV prevention<sup>1</sup> with increased uptake observed globally and in the United Kingdom.<sup>2,3</sup> Yet, evidence indicates that few women in the United Kingdom, and across Europe more widely, know about PrEP, have access to it,

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or see it as relevant to them.<sup>4</sup> This is especially the case among racially minoritized women,<sup>5,6</sup> who have increased prevalence and incidence of HIV, amid wider inequities in sexual and reproductive health and linked colonial legacies, structural racism, and sexism.<sup>7</sup>

In the United Kingdom, while the overall number of HIV diagnoses is falling in all population groups, women make up over a quarter of new diagnoses annually.<sup>8</sup> Although these data include cisgender (cis) and transgender (trans) women (i.e. women who were (cis) and were not (trans) designated 'female' at birth), few such data are available specific to trans and non-binary people (i.e. non-binary referring to people who do not identify fully or at all as female or male) because only recently have systems begun to collect gender data that are not binary.<sup>9</sup> National and regional HIV prevention programmes have had a focus on gay and bisexual men, with a dearth of prevention activity specifically aimed at cis and trans women and non-binary people.

Endeavours to gather data on PrEP use or barriers to accessing PrEP, via community surveys, have broadly failed to engage women.<sup>10</sup> Even when PrEP has become available, including through the England PrEP IMPACT Trial, uptake among cis women has been particularly low. The IMPACT Trial, a PrEP implementation trial, commenced in October 2017 for 36 months, providing PrEP via sexual health centres in England, for individuals who met the trial's inclusion criteria. Of 24,255 participants in IMPACT, only 333 cis women enrolled and received PrEP.<sup>3</sup> Although higher numbers of trans women (359) and non-binary people (111) enrolled in a context of concerted efforts by trans community advocates and specialist sexual health services, it is not possible to estimate what proportion of these communities this represents because census gender data remain binary.<sup>11</sup> In the first 2 years of PrEP implementation in Scotland, relatively few women began taking PrEP, with the vast majority of participants being gay and bisexual men.<sup>12</sup>

Barriers to accessing PrEP include a lack of knowledge of the prevention technology and its potential,<sup>13</sup> women's perceptions that they are not 'at-risk' from HIV and thereby could not benefit from PrEP,<sup>6</sup> a failure to provide PrEP via health or care services that are most commonly utilized by women, and health professionals not recognising that the women they encounter could benefit from PrEP.<sup>14</sup> In a recent US study with predominantly Black cis women, few of whom knew about PrEP, authors highlighted participants' 'disconnection from current PrEP marketing', and stressed the need for 'community-level PrEP education and outreach' alongside trust in healthcare providers<sup>15</sup> (pp. 497). Also in the United States, trans women voiced concerns about how PrEP would affect hormone use and called for culturally appropriate messaging specific to trans communities.<sup>16</sup>

Peer-led interventions have been shown to be an acceptable means of improving awareness of, and access to,

PrEP.<sup>6,17</sup> In the United Kingdom, gay and bisexual men considered peer support from friends and partners who used PrEP essential, '*less abstract*' and '*more trustworthy*' than general information about PrEP.<sup>17</sup> In the United States, qualitative assessment of a PrEP intervention for cis and trans women found its '*women-focused approach*' and '*peer outreach and navigation*' to be key factors facilitating uptake<sup>18</sup> (pp. 3987). Thus far, cis and trans women have rarely been involved in such programmes in the United Kingdom.

Peer and community-led interventions have become widespread in HIV prevention and treatment internationally<sup>19</sup> and patient and public involvement in healthcare is increasingly emphasized in the United Kingdom.<sup>20</sup> Yet the extent to which community members have decision-making powers over intervention design, delivery and evaluation, and that such interventions challenge power imbalances between health professionals and communities, and structural conditions of health inequalities, are highly variable.<sup>19,21,22</sup> Prior work has also raised questions of who constitute 'peers',<sup>19</sup> who gets to represent their communities,<sup>23</sup> in which spaces, and on whose terms.<sup>24</sup> Authors across diverse disciplines differentiate between 'utility'-oriented approaches focused on often top-down delivery and 'effectiveness' and those grounded in Freirian principles of emancipatory education and social transformation.<sup>19,22,25</sup>

PrEPster is a grassroots, community-led programme, situated within The Love Tank CIC, a UK non-profit company, that aims to '*educate and agitate for PrEP access in England and beyond*'<sup>26</sup> (pp. 1). In 2019, PrEPster was awarded funding through Public Health England's (PHE) Innovation Fund for 'MobPrESH' (Mobilizing for PrEP and Sexual Health). This 12-month, peer-led pilot in England sought to work with cis and trans women and non-binary people who were transfeminine or '*assigned female at birth*', from communities most affected by HIV<sup>27</sup> (pp. 2). MobPrESH aimed to support '*increased knowledge, awareness & understanding of PrEP, alongside related sexual health issues for women*'<sup>27</sup> (pp. 2). In doing so, a key goal of the project was to '*improve equality of access to information about PrEP as a prevention strategy, mitigating wider HIV-related disparities affecting currently underserved populations*'<sup>27</sup> (pp. 2). The organization's prior experience of delivering peer education informed the development of the intervention. The programme was based theoretically on a model of peer-led, community-based health promotion using a reproductive and sexual health and justice framework, which attends to intersecting social identities such as gender, race, and class (Zakiya and Kristin<sup>28</sup>, pp. 1); related injustices and power structures; and seeks community-led responses.<sup>28,29</sup>

Between January and December 2019, staff at PrEPster worked in London, with two partner organizations in Bristol (Brigstowe) and Yorkshire (MESMAC), to recruit,

train, and support volunteer peer mobilizers, providing them with ‘resources to develop PrEP and sexual health interventions in their own communities’ with a view to ‘build[ing] capacity for community responses to HIV’ and ‘creating skilled peer mobilisers who can educate and talk about PrEP’<sup>27</sup> (pp. 2). The project aspired to work with cis and trans women and non-binary people across a wide age range, prioritizing recruitment of communities most affected by HIV, and specifically women and non-binary people who are Black, people of colour, trans and/or migrants, inclusive of sex workers. With the support of project staff, peer mobilizers sought to engage with people they were connected to socially, religiously, and/or professionally, via diverse formats, audiences and settings, including organized events, discussion groups, creative activities, and *ad hoc* conversations, to discuss PrEP and sexual health (see MobPrESH evaluation report<sup>30</sup> pp. 15–17 for further details).

PrEPster commissioned two researchers (PG and SR) to undertake a process evaluation, to establish key learnings from the pilot. This aimed to explore MobPrESH’s accessibility, feasibility, acceptability, and ‘fidelity’ (i.e. to what extent it was implemented as intended), from the perspectives of peer mobilizers and project staff, using qualitative methods. We sought to answer four questions: What are peer mobilizers’ and project staff members’ experiences of MobPrESH? What opportunities and challenges have they faced? How accessible, acceptable, and feasible was participation in MobPrESH for peer mobilizers, including members of specified priority communities? What was the fidelity of MobPrESH?

## Methods

Between August and November 2019, SR and PG conducted a qualitative process evaluation involving two focus group discussions and two interviews with nine MobPrESH peer mobilizers in Bristol and London (out of a total of 14 invited to participate), and six interviews with project coordinators and managers (‘project staff’) across all three sites. We used a critical participatory action research approach, which seeks to involve communities (in this case, MobPrESH peer mobilizers, staff and members of MobPrESH priority communities) in generating knowledge about them, drive-related action, acknowledge and challenge power relations of research and practice, in support of social justice.<sup>31,32</sup> First we detail each of our positionalities as co-authors, in terms of our relationships to topics of PrEP and sexual and reproductive health, and the communities MobPrESH aimed to serve, to help contextualize subsequent description of our approach. PG is a white queer cis woman who does participatory qualitative research with sex workers and other underserved communities about (sexual) health, rights, and social justice. SR is a brown cis woman who does qualitative and economic

research on HIV and PrEP with underserved communities. JC is a Mixed Black Caribbean queer cis woman who works with underserved communities on (reproductive/sexual) health justice issues. WN is a white queer cis man, with current experience of using PrEP. He coordinates PrEPster/the Love Tank Inc – a community-based health promotion non-profit organization that promotes the health and well-being of underserved communities including LGBT+ people, people of colour, migrants, and sex workers. JC and WN developed and led MobPrESH.

PG and SR contacted peer mobilizers via project staff – who invited all current MobPrESH peer mobilizers via email or phone to participate (‘purposive sampling’) – and explained the purpose and confidential nature of the evaluation. We sought to include as many of the peer mobilizers and project staff as possible across the three sites, reflective of the diversity of recruited peer mobilizers, and to generate data on the range of peer mobilizers’ and project staff members’ views and experiences of the programme. Peer-mobilizer participants included eight Black cis women and one white cis woman, volunteering in/near Bristol and London. Project staff included three Black and two white cis women and non-binary people, and one white cis male, of heterosexual, queer, and bisexual identities.

We used topic guides (one with peer mobilizers, one with project staff) to explore experiences of joining MobPrESH, training, designing, and implementing project activities; likes, dislikes, and expectations; what worked (less) well; factors that made each aspect easier or more difficult (e.g. training, time, funds, skills, support from coordinator, belief in project, prior experiences, support networks, (emotional) labour, competing priorities, and commitments); perceptions of how peer mobilizers’ interactions affected people’s knowledge of PrEP, other sexual health services, and how to access them; how the project worked with pre-defined priority groups in practice; and recommendations for future projects. In interviews with project staff, we explored these issues from their perspectives as well as asking about how they recruited and worked with peer mobilizers, and how they worked with partner organizations.

SR and PG conducted audio-recorded focus groups and interviews at PrEPster, partner organizations, the London School of Hygiene & Tropical Medicine (LSHTM) and via phone/Skype (interviews only), in private rooms where no one other than the participants and the researchers were present. On average, focus groups and interviews lasted 84 and 65 min, respectively. All participants provided prior written informed consent. Refreshments were provided, and peer mobilizers were able to claim for travel and childcare expenses from MobPrESH in the same way as for project activities.

PG and SR used audio recordings to write detailed field notes, noting verbatim quotes that illustrated key

emerging themes, for each focus group and interview (resources available precluded full verbatim transcription). Our sampling was guided by the finite number of peer mobilizers and project staff involved in the project rather than possibilities to achieve theoretical saturation. Nevertheless, within the data we were able to generate, common themes emerged within and across sites. For each site, we reviewed focus group/interview field notes, and made comparisons between and within them, to identify key emerging themes – cutting and pasting notes and quotes under the relevant theme heading(s) in Microsoft Word – and synthesized these in a detailed analytical summary. Where a sufficient number of people took part to protect anonymity, the site-specific analytical summary was shared with peer mobilizers and project staff, including JC and WN, for their comments. Summaries were revised accordingly and synthesized, contrasting findings across and within sites to refine themes and generate recommendations. With input from JC and WN, SR and PG presented initial findings at the peer mobilizer celebration day in November 2019, during which we received additional feedback from peer mobilizers and project staff from across the sites, including those who did not take part in the evaluation itself. Finally, an earlier version of the final evaluation report was shared with project staff and peer mobilizers across partner organizations for consultation. Names and identifying information are excluded, in keeping with the anonymous nature of the evaluation. This evaluation received ethical approval from the LSHTM ethics committee (REF: 17634).

We sought community input on research questions, tools and methods, data interpretation, and dissemination. Prior to data collection, PG and SR sought input into the topic guide from JC, WN, and, via them, other project staff and peer mobilizers, to ensure that the questions were appropriate, acceptable, and meaningful to participants. During data collection, SR and PG used open-ended questions and sought to foster spaces in which participants could talk openly, frankly, and safely about their experiences. PG and SR were not known previously to participants, and PG's identity, in particular, as a white cis woman may have shaped how willing, comfortable and/or safe participants felt to discuss their experiences. However, these spaces were made more possible by the relationships of trust fostered within MobPrESH among peer mobilizers<sup>30</sup> (pp. 12–15) and PG and SRs' existing relationships with PrEPster staff including JC and WN. During analysis, we sought to centre peer mobilizers' accounts and particularly those whose racial, religious, and/or gender identities were most minoritized and marginalized, complementing these with project staff accounts while avoiding the latter overshadowing the former. During this process, we kept in mind the power dynamics between different peer mobilizers and project staff, and the communities they were working with, particularly in relation to racial and gender

identities and roles on the project. By centring participants' experiences, we sought to avoid imposing our own perspectives on PrEP and sexual health while retaining an analytical lens of racial, reproductive, and social justice in line with our respective work in this field. Seeking input from peer mobilizers during an event centred around their experiences and successes, and via individual feedback on the site-specific summaries and final report, provided further opportunity to incorporate participants' perspectives in the analysis process. This input, along with feedback from project staff, provided important qualifications to all themes, and particularly 'navigating silence and stigma'; 'connecting within and across communities'; and 'competing pressures and structural hostilities'.

## Results

The process evaluation report is publicly available.<sup>30</sup> Here, we present five main themes – derived through refinement of the six themes identified in the evaluation report – of relevance and transferability to peer-led PrEP and sexual health programmes with women and non-binary people: connecting and relating to situate sexual health discussions; navigating silence and stigma; connecting within and across communities; competing pressures and structural hostilities; resources and continuity.

### *Connecting and relating to situate sexual health discussions*

Connecting and relating were key to initiating and situating PrEP and sexual health-related discussions in the context of people's lives and desires for information. Peer mobilizers and project staff noted that visible cues, such as wearing and displaying 'PrEPster gear' (e.g. badges, stickers, t-shirts, postcards), and the specific focus on PrEP, helped spark curiosity and interest ('*People wonder, 'what's this about?''*'; peer mobilizer). This, in turn, could lead to lengthy discussions during events and everyday interactions. While some peer mobilizers focused on reaching out to people they already knew, one described initiating spontaneous discussions based on interest from strangers ('*If I had three to four women [e.g. in the park] and they wanted to have a conversation, I would just do it'*'; peer mobilizer). In Yorkshire, although some people were initially a bit '*taken aback*' when peer mobilizers initiated discussions in hairdressers, these encounters sparked '*seeming interest in furthering those conversations*' (project staff) and led to salons displaying PrEP-related materials.

Peer mobilizers and project staff noted that, prior to encountering MobPrESH, most peer mobilizers had little to no knowledge of PrEP. Some, and many of the women they talked to, were also unaware of advances in HIV treatment (e.g. that a person living with HIV who has an



undetectable viral load cannot transmit the virus to others) and where PrEP, HIV testing, and sexual health services could be accessed. Other peer mobilizers had engaged in HIV-related activism for many years. MobPrESH activities thus required intensive and varied dialogue. Although some peer mobilizers were not involved in MobPrESH for long, project staff felt that they had ultimately ‘*learned a lot and . . . were empowered to go and have those conversations*’.

Despite some reluctance to engage in discussions, peer mobilizers encountered considerable interest in hearing about PrEP and other aspects of sexual health. Peer mobilizers and the communities they engaged with questioned the lack of information ‘*out there*’, conveying a sense of urgency to inform themselves and others:

People are asking, ‘Why don’t we know?’ (Peer mobilizer)

I had no idea what it was, how accessible it [PrEP] was, and I’m wondering why is it not in people’s faces? (Peer mobilizer)

Peer mobilizers and project staff highlighted the importance of materials and activities that people could relate to, in the absence of messages from people ‘*who look like you*’:

When you’re speaking with Black people and they see a Black face [woman on front of PrEP leaflet] they resonate immediately, and they want to hear. (Peer mobilizer)

You know how TLC used to wear condoms on their jackets? I’ve always wanted to do something like that . . . for teenagers . . . get rid of whatever the shame or the stigma is . . . fun and lighthearted with music and all that retro 90s stuff . . . if there’s no one relatable putting the message across . . . you feel there’s no one to . . . talk to, if no one looks like you, no one shares the same issues as you. (Peer mobilizer)

Peer mobilizers sought to incorporate themes of PrEP, HIV, and sexual health into everyday conversations, so that it felt ‘*a bit less of a pitch*’:

I try not to force it down, but whenever the opportunity creeps in, for example something on the news, or my little sister talks about sex ed class . . . I’ll be like, ‘Oh that’s really nice, I’m doing something similar to that’ . . . just telling them things I’ve learned. It helps. (Peer mobilizer)

One peer mobilizer ‘*plant[ed] the seed*’ by gently linking the conversation to women’s broader concerns (‘*A lot of women were really interested in speaking about [condom negotiation] . . . it opened . . . doors*’; peer mobilizer), supported with statistics and discussions around why women might not attend health services. Another described tailoring messages, resources, and formats to the needs, knowledge, and expectations of her community, specifically Muslim women:

I made sure the message over PrEP was there, but also gave them an opportunity to discuss what was on their mind. (Peer mobilizer)

Interactive formats helped to alleviate apprehensions, while building informal discussions around creative activities removed the formality and pressure of more structured, didactic interventions:

We had a pizza evening with a younger [LGBT] group, we painted a poster . . . because the space was less formal there was less of a barrier, we were able to have these little conversations as opposed to this big formal lecture type thing . . . painting and talking. (Peer mobilizer)

[It] takes the pressure off a sexual health conversation, makes it much easier to have good connections, got something lighthearted as well as the serious stuff; people . . . don’t feel like they’re getting an intervention on them. (Project staff)

Making these connections involved varied emotions. When women did not show up to her first group session, one peer mobilizer described ‘*hit[ting] a rock*’ about which she still felt unsatisfied. Yet ultimately engaging women in informal and impromptu conversations about PrEP were her ‘*most successful and happiest moments*’ during which she felt ‘*very proud*’. Learning about PrEP was a ‘*revelation*’ for some and MobPrESH ‘*enlightening*’, ‘*enriching*’, and ‘*empowering*’. However, some peer mobilizers felt anxious, awkward and/or pressured before engaging in discussions and were concerned how people in their communities would react (‘*Would I be accepted [in my community]? People are conservative and Muslim women in particular do not like to speak about sexual health openly*’; peer mobilizer) – patterns that project staff also mentioned. Peer mobilizers dealt with this by seeking advice from project staff and other peer mobilizers, planning a mental ‘*tool kit*’ for different situations, building up conversations gradually, and initiating discussions on social media.

Connecting and relating, situating discussions in the context of people’s lives and desires for information, and preparing for related emotional effects, thus had important implications for the acceptability and feasibility of MobPrESH, for peer mobilizers and the communities they sought to serve.

### *Navigating silence and stigma, creating trusted spaces*

Most peer mobilizers anticipated and/or experienced some reluctance to talk about PrEP and sexual health and discussed how they sought to navigate these silences, with implications for the acceptability, accessibility, and feasibility of the project. Some women who one peer mobilizer encountered were initially concerned about how their information would be (mis)used by

a government-funded project. More frequently, peer mobilizers linked silence to blaming discourses around HIV, bodies, and difference, reinforced through language, lyrics, and assumptions that HIV only affects gay men and '*PrEP makes people more promiscuous*' (peer mobilizer). Peer mobilizers highlighted the influence of social, religious, and legal oppression of sexual and gender minorities, particularly where colonial-era laws criminalizing homosexuality persisted – as reflected in this exchange between two peer mobilizers:

In the Caribbean and certain parts of Africa where it's actually illegal to be gay . . . even having that conversation, where do you start?

With a history lesson.

You literally have to go to colonial-, oh my god, it's so much. It's all conditioning as well . . . so much to unpack. (Peer mobilizers)

Peer mobilizers anticipated difficulties engaging with Christian and Muslim women, particularly where men were present – yet one peer mobilizer had considerable success with women in her local mosque, leading her to be invited to two other cities:

They told women in their group what I had informed them about PrEP and they said they'd like me to come . . . I was really amazed at this progress, the power of the word of mouth. (Peer mobilizer)

Project staff considered this testament to the quality of peer mobilizers' work and ability to reach out within and beyond their communities.

Peer mobilizers and project staff noted that some women had voiced concerns that participating in MobPrESH events and discussions would imply that they were living with HIV, '*promiscuous*', and/or mistrusted their partner. One peer mobilizer linked this reticence to HIV-related blame, compared with conditions not perceived as a person's 'fault'. Women who were living with HIV but were not public about their status worried that participating could out them to partners, families, and communities.

Peer mobilizers and project staff described various ways in which peer mobilizers navigated these silences and related stigmas. One peer mobilizer described how, after low turnout at a larger group discussion, impromptu '*mini sessions*' (peer mobilizer) with women who knew each other had allowed them to talk discreetly without embarrassment. Another produced small, inconspicuous leaflets, to let refugees and people seeking asylum know where they could access information and support. She also sought a slot at an existing forum to reach women who she felt would not come to an advertised PrEP event. Two

others stressed in discussions that PrEP allowed women to make choices and protect themselves:

I tried really hard to make people aware that you don't have to be sleeping around to get HIV, you can be a most faithful wife . . . [you might not] know what your husband is getting up to, as a woman you have a choice, if you have PrEP to protect yourself with. (Peer mobilizer)

Others sought to undo homophobic and other conditioning, bolstered by training that had equipped them to challenge preconceptions safely and initiate hitherto off-limits conversations, particularly in religious and/or family environments:

I like to ask questions . . . 'What would you do if . . . you had a family member like this?' You kind of recognize . . . maybe they don't feel that badly against the situation, it's just the things that they've . . . been learning ever since they were little. (Peer mobilizer)

The whole programme has made me more confident to have conversations . . . with people about HIV and sexual health. Before it was really awkward and my background . . . is majorly religious, growing up in the church . . . we do talk about sex but . . . there are a lot of boundaries . . . places that you can't go . . . [Now] I can go up to my mum and be like, 'I'm learning about this' and she's happy about that. (Peer mobilizer)

Some compared this to the privilege of safe family and school environments that had allowed them to talk openly, and intergenerationally, about sex and sexuality:

My parents are more open-minded . . . the views back home, they have that inside of them, but living here a long time they have been exposed to different things and they've come to different conclusions . . . my privilege is to have parents who sat me and my siblings down to talk about sex, created the safety in our home. (Peer mobilizer)

At my daughter's school they have a lot of conversations and it's really healthy . . . I was having a conversation with her and I was being really awkward, 'When you're older you might have a boyfriend or you might not even have a boyfriend, you might have a girlfriend' and she was just like, 'Mummy, I know!' (Peer mobilizer)

Embedding PrEP discussions in existing, trusted spaces of relevance to community members' lives was ultimately a major motivation for taking part in MobPrESH:

That's what makes me want to do this even more, giving something back . . . giving them permission to feel alright about whatever it is they don't feel ok about . . . At first people just want to feel safe and that someone in the room understands . . . [it] makes people be a bit more open . . . comfortable. (Peer mobilizer)

### Connecting within and across communities: what it means to be a peer

Peer mobilizers variously described their role with MobPrESH as ‘*friendship with purpose*’ and ‘*an extension of family*’:

It feels very normal to me to speak to people . . . I’m always looking for pockets of community . . . mum advised if I ever feel lonely to go to the local African Caribbean centre and just do stuff . . . I’ve always done that, it helps me to stay grounded. (Peer mobilizer)

For some, being a peer mobilizer meant feeling ‘*safe*’ and ‘*equipped*’ to talk to people. For others, it involved responsibility and ‘*a bit of pressure to deliver*’.

Project staff considered peer mobilization, ‘*not coming from outside. . . like, ‘Why can’t we help them?’*’, but led by people who ‘*look like or have some similar experiences to people in need of PrEP or who should know about it*’. This included shared ethnicity, language, age, experience of the kind of sex they had, and navigating sexual and reproductive health services. PrEPster had sought to move away from the more usual ‘*volunteer profile*’ of other HIV organizations, instead seeking:

People who have some level of political or activist sensibility. [In London] one or two are in their early 20s, most are in 30s and 40s, most are Black or brown . . . quite articulate around sexual and reproductive health . . . [able] to jump into a crowd and talk about sex. (Project staff)

Although this had created ‘*insider outsider perception[s] of the project*’ (project staff), one project staff member felt that PrEPster’s reputation as ‘*edgy*’ and peer-driven had facilitated engagement: ‘*[People say] ‘I love the work that you do, I engage with it, I know it comes from people like me’’*’.

Peer mobilizers often set out to engage with groups they were part of, including Black women and women of colour, Muslim women, asylum seekers and refugees, younger people, and trans women (‘*We go where we know*’; peer mobilizer). Most also engaged people of nationalities, ethnicities, generations, and genders different from their own, which helped to foster mutual understanding:

My community is very diverse, I could bump into 10 nationalities in a 2-minute walk. (Peer mobilizer)

We were all Black there, but upon going to further events with the LGBT community . . . it helped me to understand people who are different from me . . . with different sexualities, especially in my community, I now understand how hard it is to come out to everyone, not having anyone to speak to, how are you supposed to learn? I have a friend who is bisexual and I didn’t know how to talk about it . . . now I feel better equipped. (Peer mobilizer)

That older generation that I spoke to . . . it was generally older African and Caribbean women . . . I didn’t expect it to go so well but it did . . . by the end everyone was very open . . . I just think communication is everything. Intergenerational especially. (Peer mobilizer)

Although partner organizations had initial concerns over training peer mobilizers with different gender identities and religious beliefs together, this diversity had ultimately been a strength, allowing peer mobilizers to unite around ‘*a common cause*’:

We had a deaf woman who’s living with HIV . . . people from quite different communities, different ages, different places lived . . . people took a lot away from the day, a lot of really vital information. (Project staff)

Several project staff and peer mobilizers voiced their belief and pride in MobPrESH’s focus on Black women and women of colour, given how neglected they had been in sexual and reproductive health programmes to date. Yet some also voiced and/or encountered resistance to this focus:

It was really difficult to get them to understand that this is for you, this is for us . . . they were a little bit arguing, ‘no we have to consider them [men] too’. (Peer mobilizer)

[People ask] ‘Why are we only focusing on Black women? Really defensive . . . I understand’. (Peer mobilizer)

One peer mobilizer in Yorkshire felt that Black women reaching out to other Black women singled them out unnecessarily and, after lengthy discussions with project staff where this disagreement could not be reconciled, ultimately withdrew from the project. A few peer mobilizers in Bristol felt that this focus could reinforce blame (‘*I’m sick and tired of hearing ‘BME [‘Black & Minority Ethnic’] group is very high’ because it makes them look irresponsible*’) and miss other groups with rising prevalence. One, who lived in a predominantly white town, had organized discussion groups attended by Black, Asian, Latinx, and white women and men, partly because of the composition of her existing networks but also out of her sense that ‘*everyone should be targeted*’. One project staff member considered this a matter of ‘*ideology*’ that could not always be reconciled with epidemiological data:

No matter what you say about the epidemiology of it, there are people who say, ‘Why can’t we just talk about women, why do we need to talk about race?’ . . . I believe in the process I’m doing, I think there’s a dearth of people taking this kind of approach . . . It’s easier for people to think about sexual health for group they’re not in. Aunties will say, ‘I need to tell my daughters this’ . . . looking at the epidemiology . . . ‘you need to tell your friends’. (Project staff)



The peer-led design and implementation of the project, and what it meant to be a peer to different peer mobilizers and project staff, thus had important implications for the acceptability, accessibility, and feasibility of the programme. This also had implications for the project's fidelity – in terms of the extent to which peer mobilizers did/not work exclusively with MobPrESH's priority communities.

### Competing pressures and structural hostilities

Peer mobilizers highlighted the necessity of spaces that 'empower' women, in the context of an over-policing of their bodies, expectations that they protect their partners' sexual health, gendered double-standards and related 'slut-shaming', notions that sexual violence activism limits men's freedoms, and broader neglect of women's health promotion. They linked the absence, and importance, of projects like MobPrESH to prevailing structural racism and misogyny. One peer mobilizer linked the lack of access to PrEP to HIV no longer being seen as a 'white man's problem': 'Now that the problem belongs to the BAME [Black, Asian & Minority Ethnic] community. . . we're not receiving enough attention'. (Peer mobilizer). Another noted that racial and class privilege meant that 'a lot of my middle-class white friends, even if they don't have a lot of information about HIV, if shit goes down, they'll still be OK'. (Peer mobilizer). These power relations were also reflected in how MobPrESH operated in different locations. For PrEPster – whose staff were predominantly Black and many volunteers were people of colour and/or trans people involved in contemporary discourses around racial and gender identity – it had been easier to articulate the 'racial and gender identity politics' of the project, relative to partner organizations, one of which had predominantly white staff.

Project staff described other systemic pressures and hostilities that had hindered intended recruitment of peer mobilizers from some MobPrESH priority communities and engagement with others (in other words, affecting the project's fidelity) – particularly migrants, refugees and asylum-seekers, trans women, non-binary people, and sex workers – gaps that peer mobilizers also noted. In London, MobPrESH had not recruited as many migrants as hoped and just one peer mobilizer each from south Asia and Somalia. Similarly, in Bristol, they were many ethnicities and nationalities not reflected. Project staff in Yorkshire pointed to the role of enforced transience brought about by a hostile immigration system:

[On other projects] we work with migrant groups . . . a bit, but it is really short-term, with people in 'holding centres' for 4 weeks. (Project staff)

Conscious that refugees and asylum-seekers were 'vulnerable' and had 'other things on their mind' as they navigated the asylum process, one peer mobilizer had limited

activities to briefly providing information rather than 'a platform for anything else'.

Just two peer mobilizers were trans women. Although neither were able to participate in this evaluation, project staff described their extensive engagement with trans and non-binary social and support groups in Bristol, and similar plans in London. In Yorkshire, conversations at an *International Non-Binary Day* event, while 'productive', had effectively functioned as one-off interventions rather than anything 'with longevity' (project staff). In some sites, project staff explained that MobPrESH activities had clashed with Pride-related ones, at a time when trans people were fighting particularly overt transphobia during the Gender Recognition Act consultation,<sup>33</sup> which they felt had drained emotions and energies for this kind of work:

One of big things was . . . how much trans people have been taking on transphobia in general this year . . . I think a lot of trans people's emotions and energies have been put into that . . . [those who] would do this kind of thing [MobPrESH], I think they've been quite exhausted. (Project staff)

While project staff were glad that two trans women had considered MobPrESH a 'space safe enough to come', they had anticipated that 'explicit non-binary' imagery and language about 'self-identifying women' would attract more trans and non-binary peer mobilizers. However, they also critiqued the wording used ('Non-binary people assigned female at birth'. . . I don't think we got [that] completely correct. . . what we meant was non-binary people who may be read as female'; project staff) and recommended more prior consultation with non-binary people in future. In London, PrEPster had since had more trans people join as volunteers who had not been available or aware of MobPrESH when it began.

Some project staff also voiced disappointment at not having recruited any 'out' sex workers as peer mobilizers. In Yorkshire, one linked this to 'anti-sex worker rhetorics this year' that had gone 'hand-in-hand' with transphobia: 'There has been quite the double attack on those communities which has taken away the energies' (project staff). This was in the context of fierce debate and hostile media coverage surrounding a 'managed zone' in Leeds allowing adults to sell sex on street from 7 p.m. to 7 a.m. without fear of arrest.<sup>34,35</sup>

Competing priorities, pressures and support needs also appeared to have played a part. In Yorkshire and Bristol, sex worker support services felt that the project would not work with their service users because they were generally seeking support, and would need compensation for participating in activities. In London, no peer mobilizers had talked publicly about doing sex work but some were privately supportive and/or had been involved, and discussions during training were designed to be sex-worker 'inclusive' and 'positive' (project staff). In previous projects with male sex workers, PrEPster had paid what they



would otherwise have earned for an hour of work, but this had not been possible on this project and would have caused ‘*huge inequity*’ (project staff) between peer mobilizers. It is also important to note diverse realities and inequalities within sex-working communities, affecting income and the extent to which sexual health can be a priority relative to other aspects of health, welfare, and rights.

A key reason some peer mobilizers disengaged from the project periodically or permanently was their health and social care needs. One peer mobilizer described being unable to take part in MobPrESH activities during periods of ill-health. Similarly, project staff described how the complex social care needs of some peer mobilizers in Yorkshire meant that they had ultimately had to withdraw. Project staff sought to support peer mobilizers’ needs where possible but had limited capacity to do so and inevitably these efforts left them with less time for delivering other intended activities.

These structural pressures and hostilities thus presented important challenges in terms of how feasible and accessible, it was for members of these communities to become peer mobilizers. They also shaped how possible it was for MobPrESH to be implemented as intended – in terms of which communities the project served, how many peer mobilizers could be recruited and how involved they could become, and the capacity and time project staff had to support other planned activities.

### Resources and continuity

Major constraints on MobPrESH project activities were time, related capacity, and funding, each of which affected the project’s accessibility, feasibility, and fidelity. Although peer mobilizers had done significant work, there was consensus that the short duration of the project, and the part-time project coordinator posts, had limited capacity to recruit the anticipated number (48–72) of peer mobilizers, forge links with communities, and engage in MobPrESH activities – particularly given the project’s ambitious breadth:

A project with such a wide pool of people to work with . . . in such a short amount of time is very difficult, six months . . . to get it set up, to get people interested . . . trained, to give it the time to dedicate to it and then for it just to end. But that’s no-one’s fault in terms of who was involved, that’s just the constrictions of the funding, the bid. (Project staff)

Yet our findings also highlighted potential benefits of this approach beyond pre-identified project metrics and outcomes. The project timeline and budget reflected pressure to demonstrate cost-effectiveness (*‘It’s partly the game everyone plays . . . we want to get funding’*; project staff), itself complicated by difficulties measuring and anticipating the outcomes of projects striving for long-term social change:

Peer education when it’s done well is really effective but there’s also a cost attached to it . . . The work I’ve done over

past 25 years is a direct result of joining a peer education project . . . if I was the only outcome 25 years later of that £16,000 investment in a project that recruited 12 men over 18 months . . . it was worth every single pound that was spent on it . . . We won’t see the benefit of that from MobPrESH for years. We don’t know if [peer mobiliser name] is going to . . . get a job in sexual health and be a complete star. (Project staff)

Project staff variously emphasized the number of people interacted with during events (*‘[At the Fringe festival weekend] 3-4 PrEPster staff ran 12 events over 2 days, 300 people came’*) and their sense that peer mobilizers most ‘*empowered*’ by the project were not necessarily those who had ‘*got [most] done*’ in measurable outputs. One project staff member highlighted the ‘*ripple effects*’ of onward conversations that ‘*will have changed some people’s views. . . made a difference*’ but that were not ‘*recorded officially as volunteering*’ and thus not possible to ‘*tangibly report on*’.

For some peer mobilizers, MobPrESH had given them confidence, and a sense of legitimacy. For others, it offered ‘*another angle*’ for their existing HIV activism. Yet, because PrEP involved medication, peer mobilizers were ‘*very wary of saying they had knowledge about it*’ (project staff). In one site, for more technical questions (e.g. about hormone interactions), peer mobilizers had needed to consult with project staff, in a context of rapid developments in research. One project staff member proposed that future projects rely more on expert peer project coordinators, while conceding that more ‘*basic*’ volunteer work could be patronizing to peer mobilizers. They described an alternative approach, now being used in a peer-led project for queer men of colour informed by the experiences of MobPrESH, in which a full-time paid project coordinator recruits and trains volunteers to support specific activities:

The model we used to recruit, train volunteers, ‘What would you like to do?’ I would turn on its head . . . then if the project coordinator has no volunteers, it doesn’t mean nothing happens . . . I would pay someone like [Bristol-based project coordinator] full time . . . a peer but one with key skills with the ability to deliver interventions themselves and then train volunteers to support her in delivering those interventions . . . peer mobilisers would still have opportunities to bring their own ideas, for example in month 3, but these would be planned and coordinated. (Project staff)

Peer mobilizers with competing work, studying, and caring responsibilities had not been able to commit to as many events as they would have liked. Yet several voiced their intentions to continue beyond the project’s funded period:

I know the project ends this year but hopefully after that, if I stay in contact with [the project coordinator] . . . I will be able to continue and do more, that’s something I want to do for the future. (Peer mobilizer)

I still feel like I'm very much at the beginning of this journey.  
(Peer mobilizer)

The larger partner organizations had been able to offer alternative volunteer opportunities, whereas PrEPster – without funding to continue the project – had directed peer mobilizers to other HIV organizations locally. Project staff across sites stressed the need for sustained funding for peer-led projects focused on Black women's health, alongside institutional action:

I think everything that needs to be done is being done by [organisations delivering MobPrESH] to be honest. Everything else that needs to be done is by people at the top, that's where the problem is. (Peer mobilizer)

## Discussion

We document a grassroots, peer-led project that has worked with diverse communities across three distinct UK sites – primarily Black women and women of colour who are rarely centred in sexual health projects in the United Kingdom.<sup>36</sup> Amid prevailing silence, intersecting stigma and oppression, and misinformation surrounding HIV and sexual health, peer mobilizers and the communities they engaged with demonstrated an urgency for acquiring knowledge about PrEP and broader sexual and reproductive health. They engaged most in discussions when women from their communities connected with and related to them, sharing (rather than imparting) knowledge and fostering trusted, safe spaces for open discussion, with relevance and sensitivity to their lives, needs, and experiences in healthcare. Through peer-led training and activities, the project had created opportunities for mutual learning and understanding, both among peer mobilizers themselves and the communities they engaged with, centring on what mattered most to them. The project highlighted the importance of everyday conversations and their '*ripple effects*' beyond narrow, predetermined metrics of success, in addition to more formal health promotion activities. It also challenged the notion of populations that are 'hard to reach'<sup>37</sup> and traditional approaches of working with communities grouped by singular dimensions of identity and lived experience.

The project also faced several challenges. A primary limitation was that of resource and capacity. Project staff and peer mobilizers across sites recommended longer for future projects, particularly to recruit peer mobilizers and build connections with communities. Although MobPrESH was able to work with diverse communities, the project had difficulties recruiting sex workers in all sites, and migrants, refugees, asylum-seekers, trans women, and non-binary people in some sites, amid competing pressures and structural hostilities. Furthermore, supporting peer mobilizers' health and social care needs – and the emotional dimensions of the work – required resources, expertise, and ultimately limited some women's capacity

to remain in the project. This evaluation highlights important structural challenges that affected how feasible it was for project staff to recruit and support different communities of women and non-binary people, and for peer mobilizers from these communities to access the project. These challenges ultimately, therefore, affected the extent to which MobPrESH could be implemented as originally proposed, that is, its fidelity. Yet, they also illuminate the often unseen/unmeasured labour of projects led by marginalized communities who lack access to structurally competent services, in contexts of colonial and patriarchal legacies, persisting institutional racism, misogyny, transphobia and anti-sex-worker sentiment, austerity, and criminalization.<sup>38-40</sup> Furthermore, they highlight how oppressive forces that contribute to the disproportionate impact of HIV on racially minoritized and marginalized communities also influence possibilities for these communities, involvement in programmes aiming to challenge these forces.<sup>9,40,41</sup> Peer-led projects for and by communities that have been neglected in mainstream service provision, policy-making, and research are thus likely to require more, not less, resource commitment. Research in the United States highlights how women were less likely to consider taking up PrEP if they had insecure housing, co-occurring health conditions, and caring responsibilities, and more so if health and social care services were offered. As a result, the authors recommended embedding PrEP in the latter, alongside peer- and structurally competent interventions.<sup>18</sup>

During focus groups and interviews with peer mobilizers and project staff, it was apparent that many peer mobilizers, particularly in London, supported a focus on Black women and women of colour, but some were concerned that this stigmatized and discriminated against these communities – highlighting important issues around the project's acceptability to peer mobilizers. PrEPster felt well-positioned to navigate these politics and those relating to gender identity, partly because of their staff and volunteer make-up. Partner organizations, by contrast, had prior concerns around bringing together peer mobilizers of different religious beliefs and gender identities, although ultimately recognizing this as a strength. This highlights the complexities of peer-led interventions but also the necessity of acknowledging linked power imbalances – including between project staff and peer mobilizers – and being explicit from the outset about the political/transformational goals of such projects, in a context of deep colonial and patriarchal legacies in sexual and reproductive health interventions and research.<sup>7,38,42</sup>

There are a number of limitations to this research. The first of these relates to who participated. We were unable to speak with peer mobilizers in one of the sites because of their short-term participation in MobPrESH, or with the two trans women peer mobilizers. Although we gained valuable insights from project staff and at the peer mobilizer

celebration day, focus groups or interviews with these peer mobilizers would likely have generated richer information about their experiences and perspectives. The second limitation relates to how we recruited participants, generated data, and our positionalities and roles. Recruitment via project staff may have influenced peer mobilizers' decision to participate, but their established relationships made this the most appropriate and effective approach. Conducting focus groups helped to identify themes of importance across perspectives/experiences, but it may also have precluded accounts that participants were less willing to share publicly. PG and SR being unknown to participants, and PG's identity in particular as a cis white woman, may also have limited how willing and safe participants felt to share their experiences, and indeed their desire to participate at all. Yet those who did participate described how MobPrESH had fostered a space in which they could talk openly with other peer mobilizers<sup>30</sup> (pp. 12–15). The fact that SR and PG were independent of MobPrESH might also have made it easier to voice any concerns or critiques. Finally, not transcribing interviews/focus groups verbatim necessarily limited the depth and nuance of analysis. However, PG and SR listened back to the audio several times and wrote detailed notes, including verbatim quotes where relevant. As described in the 'Methods' section, we sought to centre peer mobilizers' experiences rather than imposing our own perspectives on PrEP sexual and reproductive health. Feedback from peer mobilizers and project staff on site-specific summaries, our emerging findings, and the draft report, helped to ensure we reflected their experiences of the project appropriately.

For future peer-led projects, we recommend explicit, upfront explanations around their transformative goals and what it means to be a 'peer'. We also urge collective critical reflection across and within organizations about how power, privileges, and oppressive forces – in relation to race, gender (identity), class, migration status, disability and other aspects of lived experiences – affect how such projects are funded, staffed, managed, and implemented, and how these power relations need to be challenged to centre the needs of women and non-binary people most impacted by HIV. Offering payment to all peer mobilizers – or, if adequate resources cannot be secured, payments that can be donated back/paid forward by those who do not feel they need them – could help to improve accessibility to the most marginalized individuals and communities. More extensive prior consultation with a diverse range of sex-worker, trans, non-binary, and migrant communities and organizations – supported by a longer lead-in time and trusted contacts – might help to address concerns about involvement, in the context of sexual health programmes and research that have stigmatized and neglected these communities,<sup>9,40</sup> and connections between (public) health, criminal justice, and immigration systems.<sup>41,43</sup> It is also critical that such projects are sufficiently resourced and flexible to factor in participants' diverse health and support

needs, and ideally support access to structurally and culturally competent care while challenging the policies and institutional cultures that restrict such access in the first place.

## Conclusion

MobPrESH and its evaluation have offered opportunities to learn from a short-term, experimental, peer-led project seeking to engage women and non-binary people around PrEP and sexual health, through a focus on lived experience and participation. It is crucial that such projects continue to be resourced and foregrounded, by and for the communities who need them most. This will require sexual and reproductive health practitioners, academics, and policy-makers to support communities in challenging the linked social, economic, and political structures that have precluded such funding and projects to date, and that continue to threaten the health and lives of Black women and women of colour, trans women and non-binary people, sex workers, and migrants.<sup>7,40–42</sup> Finally, there is a need to recognize that the productive potential of peer-led sexual and reproductive health projects are not easily reducible to quantitative metrics over short time periods.<sup>21,22</sup> Understanding how such projects can achieve lasting progress requires long-term commitment and community-led qualitative research. This would help to demonstrate how women and non-binary people navigate and challenge the oppressions that restrict their sexual and broader health, and drive transformative social change.

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## Author contribution(s)

**Pippa Grenfell:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Supervision; Writing – original draft; Writing – review & editing.

**Sabrina Rafael:** Conceptualization; Formal analysis; Investigation; Methodology; Writing – review & editing.

**Josina Calliste:** Conceptualization; Funding acquisition; Methodology; Project administration; Writing – review & editing.



**Will Nutland:** Conceptualization; Funding acquisition; Methodology; Project administration; Writing – original draft; Writing – review & editing.

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### Supplemental material

Supplemental material for this article is available online.

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