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‘There’s this glorious pill’: gay and bisexual men in the English midlands navigate risk responsibility and pre-exposure prophylaxis

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ABSTRACT
Pre-exposure prophylaxis (PrEP) is currently being trialed for seronegative gay and other men who have sex with men (GMSM) at risk of HIV infection in England. However, research from other countries where PrEP is available shows limited literacy and uptake by GMSM at risk of HIV. We collected focus group data from 18 GMSM (13 HIV− and 5 HIV+) from Leicester, an ethnically diverse city in the English Midlands. Data were analysed using thematic analysis and three themes are presented. The first theme ‘I can’t get my head around people like that’: Representations of PrEP users within and beyond gay communities explores how PrEP users are vilified by some GMSM and the wider media. The second theme, ‘There’s a culture of anti-trust’: PrEP, stigma and the interpersonal politics of HIV disclosure discusses how PrEP influences HIV disclosure and sexual decision-making in casual sero-discordant sexual encounters in a context where seropositive men experienced pervasive HIV stigma and HIV− men were suspicious of HIV+ sexual partners. In the final theme, ‘I’m still suspicious’: Discourses of doubt and distrust participants voiced concern over the safety of PrEP and the motives of drug companies, healthcare agencies and PrEP activists. We consider these findings through a critical lens of wider theorising around the relationship between public health agencies and GMSM communities and consider the impact of these perspectives on likely engagement with PrEP in an English context. We call for more critically informed and nuanced ways of promoting health and well-being amongst men from these communities.

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Introduction
The development of pre-exposure prophylaxis (PrEP) has been described as a ‘defining moment’ in HIV Prevention (Abdool Karim & Abdool Karim, 2011). Studies have demonstrated that daily, continuous consumption of PrEP is a safe, effective method for preventing HIV (Koester & Grant, 2015). In most countries in which PrEP is available, one drug is currently approved: ‘Truvada’, which is a compound of two antiretroviral agents. However, in a rapidly developing field of both drug development and socio-medical policymaking, there has also been clinical research into the efficacy and acceptability of ‘on-demand’ regimens whereby individuals take PrEP over shorter intervals around more episodic unprotected sex, or receive monthly or bimonthly injections, or sub-dermal implants (Elsesser et al., 2016; Greene et al., 2017). PrEP is radically altering public health policy and practice in the area of HIV prevention (De Vries & Baral, 2017) and contributes to wider contemporary public health debates around medical versus behavioural models of disease prevention.
PrEP is not the only strategy for biomedical management of HIV prevention. Post-exposure prophylaxis (PEP) has been used for several years (Llewellyn, Martin, & Nixon, 2016) whilst the use of ‘treatment as prevention’ (TasP), which involves HIV+ individuals taking medication that decreases their HIV viral load and thus reduces infectiousness, has become increasingly common. Consequently, several authors have noted concerns on the rise of the biomedicalisation of everyday sexual health practices (Dean, 2015) and debates around these interventions have on occasion led to a schism between public health agencies and healthcare providers (Persson, 2015).

In countries such as the UK, the burden of HIV infection falls disproportionately on gay, bisexual and other men who have sex with men (henceforth GMSM) with transmission typically via condomless anal sex (referred to as ‘bareback sex’) (Berg, 2009). However, despite widespread activism from members of GMSM communities, health agencies in various countries have adopted different stances on the licensing and promotion of PrEP (Brisson & Nguyen, 2017). Subsequently, awareness, availability and endorsement of PrEP vary significantly amongst GMSM in different Western countries (Bil et al., 2015; Frankis, Young, Lorimer, Davis, & Flowers, 2016).

At the time of writing, PrEP is available on the National Health Services (NHS) of Scotland and Wales but remains unavailable on the NHS in England, where demand is highest. PrEP users in England have acquired the drug online and perceived delays in its availability through statutory health agencies have been accompanied by anger and accusations of injustice (Cairns, Race, & Goicochea, 2016). Understanding these tensions fully requires consideration of the legacy of relationships between GMSM communities and health bodies throughout the era of AIDS activism (Myrick, 2016). There has been an over-simplification of risk and responsibility discourses, a history of GMSM being denied access to the most effective HIV treatments and other health and care interventions (Epstein, 1996), a wider reification of ‘healthism’ in sexual health (Epstein & Mamo, 2017) and a continued under-appreciation by public health agencies of the complexities of the roles of desire, stigma, intimacy and romance in understanding GMSM sexual relationships (Flowers et al., 1997; Race, 2010). Indeed, some GMSM view government-driven public health initiatives as ‘colonial oppression’ (Cairns et al., 2016).

In the second half of 2017 in England, a trial commenced which aims to recruit 10,000 people attending sexual health clinics, who are at high risk of HIV infection and willing to try a PrEP regime (Public Health England and National Health England, 2017). The ability to access PrEP safely and with accompanying proper health screening represents an important public health and equality issue. As indicated above, it is known that some individuals are accessing the drug through private practitioners or consuming the drug in unregulated and unmonitored form (known as ‘PrEP Sauvage’). There are several risks associated with this practice including adverse side effects on the kidneys, liver or bone health and HIV infection risk due to suboptimal adherence (Zablotska et al., 2013).

Nonetheless, as Cairns et al. (2016) point out PrEP seems to be routinely associated with ‘dissent and drama’ and there are several explanations for understanding why PrEP has not met with unanimous endorsement from statutory agencies despite its effectiveness as a HIV prevention tool. Whilst the drug is promoted as an adjunct to other HIV prevention methods such as condom usage and regular HIV testing, there have been concerns that the widespread availability of PrEP leads to an increase in unsafe sexual practices and an increase in other sexually transmitted infections against which it offers no protection, although data in this area are currently equivocal (Harawa et al., 2017; Volk et al., 2015). There are also medical concerns around toxicity and resistance if used after HIV infection (McMahon et al., 2014) and economic debates around its cost-effectiveness (Cambiano et al., 2015). Furthermore, in those countries where PrEP is more easily accessible, there appear to be relatively low levels of knowledge and uptake within GMSM communities generally (Dolezal et al., 2015; Frankis et al., 2016) and amongst those GMSM who are concerned about their exposure to HIV as indicated by attendance at HIV testing clinics more specifically (Leonardi, Lee, & Tan, 2011; Rucinski et al., 2013).

British-based qualitative research around PrEP is limited although recent research studies in Scotland (where PrEP is available on the NHS) and England have shown both perceived benefits of using PrEP which included a heightened sense of self-efficacy, self-reliant protection from HIV and
sense of control alongside a number of reservations GMSM have around PrEP use – including concerns about side-effects, drug safety and stigmatising negative labels (such as ‘Truvada Whore’) attached to PrEP users (Jaspal & Daramilas, 2016; Young, Flowers, & McDaid, 2014).

In the context of ongoing social and political debates about PrEP, additional qualitative research in this area seems timely and necessary – especially outside of what Keene, Eldahan, White Hughto, and Pachankis (2017) call ‘urban gay enclaves’ with extensive Lesbian, Gay, Bisexual, Trans* and Queer (LGBTQ) communities and services where most of the existing research has been undertaken. Therefore, in this study, we examine the views of GMSM in Leicester, a city in the English Midlands. Leicester was selected for a variety of reasons. It is a mid-size ethnically diverse city. The 2011 Census (NOMIS, 2015) which was completed by approximately 330,000 residents estimated the three main ethnic groupings to be White (50.52%), Asian or British Asian (37.13%) and Black or British Black (6.24%). Leicester is significantly more deprived than the English average, with particularly high scores relating to income and employment deprivation (www.gov.uk 2015). It has the highest levels of HIV prevalence within the region and is also a designated site for the PrEP trial. Our aim therefore was to use this particular location to understand how an ethnically and socio-economically diverse group of GMSM (both HIV+ and HIV−) felt about PrEP and to explore their views, experiences, representations and intentions.

Methods

Following ethical approval from De Montfort University, three focus groups, each of approximately 75 minutes’ duration, were held in 2017 in a LGBTQ community space. Groups were facilitated by either the first or second author who are both ‘out’ gay men, with prior experience of qualitative sexual health research. Focus groups facilitate the discussion of contested issues and allow researchers to explore how arguments are promoted, challenged and defended by participants (Stewart & Samdasani, 2014). Participants were recruited via various strategies including local LGBTQ press and social media, snowballing and flyers at Leicester Pride. In total, 18 men participated with 6 in each group. Groups One and Two were constituted of men who were HIV−. Group Three was aimed at HIV+ men but included one HIV− man who was the long-term partner of one of the other participants. His inclusion was approved by all other attendees. To help situate the sample, participants were invited to complete a questionnaire about their age, employment status, sexual identity, sexual activities including condom use as well as prior use of PrEP and PEP. They were not asked about their income or current relationship status.

Participants were UK residents aged between 24 and 48 years of age. Fifteen identified as gay and three as bisexual. They were from various occupations; several were unemployed. Using self-labels, participants described their ethnic backgrounds as ‘White-British’ (9), ‘British Indian’ (4) ‘Black-British’ (2), ‘Cypriot’ (1), ‘British Asian’ (1) and ‘British Pakistani’ (1). All HIV+ positive participants were taking Anti-Retroviral Therapy (ART). Of the 13 HIV− participants, six disclosed recent bareback sex, eight had been tested for HIV in the last 12 months, and two had used PEP. With regard to PrEP, only one participant was a regular user.

A topic guide was developed for the focus group but was used flexibly by group facilitators. Before the discussions started, each participant was invited to complete the questionnaire independently and to return to the facilitator before the group began. Participants completed and signed consent forms and were made aware that whilst they could leave the focus group at any point, any data already collected would be retained.

Discussions were audio-recorded. Participants were subsequently thanked, debriefed and given a £10 shopping voucher to compensate them for their time. Data were transcribed in full and have been analysed using inductive thematic analysis. The approach identifies salient ‘themes’ that reflect patterns of meaning across the data set. Thematic analysis is a flexible methodological approach that
affords the analyst the epistemological freedom to take an exploratory and inclusive approach to the data which is especially beneficial when researching emerging topics (Braun & Clarke, 2014).

Each transcript was initially analysed as an idiographic unit by the corresponding author in the first instance and a table of themes produced for each with selected extracts. All transcripts were also read by a second member of the team and coded independently. Members of the research team subsequently met and refined the analysis for each group before selecting key themes across the transcripts for dissemination in the present paper.

**Analysis**

Several themes were developed from the data. For the purpose of this paper, we focus on three most relevant to a critical public health audience: *Representations of PrEP users within and beyond gay communities; PrEP, stigma and the interpersonal politics of HIV disclosure; and Discourses of doubt and distrust*. All are illustrated with quotations which aim to capture our interpretations of the discussions alongside analyses of participant interactions through some more extended extracts. The analysis overall reflects the complex and paradoxical nature of perceptions around PrEP, a sense of individuals and a community ‘feeling their way’ with PrEP and the continuing challenges of cultural homophobia and HIV stigma within GMSM communities. Our discussion of the findings is embedded within a commentary of the perceived and potential role of public health agencies in providing and potentially promoting PrEP in an English context. Connections are made to theory and related research throughout.

*I can’t get my head around people like that*: *Representations of PrEP users within and beyond gay communities*

There were paradoxes in how men who were taking PrEP were viewed within the gay community with the innovation being seen as more appropriate in certain contexts. PrEP was seen as a positive development for sero-discordant couples in long-term relationships to enjoy ‘stress-free barebacking’ and ‘greater intimacy’ without condoms, and was also welcomed for young gay men to allow them a period of not worrying about HIV and recognising their lack of skills or interest in safer sex.

> Younger gays just want to go out and take a tablet and have all the fun in the world. They generally have a need for it because they need to be protecting themselves. (P14, HIV+ focus Group 3)

However, whilst young gay men enjoying the discovery of gay sex were given a licence to be ‘irresponsible’, with regard to older gay men who were expected to have greater experience and efficacy in negotiating safer sex, representations were more complex:

> When people see the word PrEP they usually think promiscuous or safe. (.) He could be seen by different people in different ways. Oh he’s taking PrEP, presumably that means sleeping with loads and loads of different people (…) or it might mean that actually this person really takes care of their sexual health, therefore my sexual health as well, as a responsible person. (P4 HIV−, Group 1)

This participant offers a measured view of PrEP users applying a counter-narrative to the idea of PrEP users as disinterested in sexual health and ‘automatically’ promiscuous. However, most of the HIV− participants reframed this idea of responsibility taking a more overtly ‘moralising’ perspective. One participant discussed an acquaintance whose Facebook profile had a photograph with Truvada between his teeth.

> P12: He’s quite promiscuous and goes out to these sex parties and things… He goes to a lot of the sort of fetish scenes in Birmingham and things like that… I’ve had the conversation about catching things but I don’t think he cares that much. He’s not that close a friend in the sense that I couldn’t really have a conversation about it with him, but I do know he’s on it because his Facebook profile had PrEP in it, in his mouth smiling.

> P10: That’s quite open isn’t it?
P12: I think that’s disrespectful personally. Run away with anything… Reckless, flaunt things in people’s faces. When I saw all of this I took a step back from the person. I don’t know how to be with this person… I find it hard to get my head around people like that.

Although the language is more measured conceptually, this practice is similar to ‘slut-shaming’ noted elsewhere (Jaspal & Daramilas, 2016). What is noticeable is not only the moralising language of disapproval (especially around exhibitionism, a lack of interest in sexual health and promiscuity) but also the social distancing invoked by the participant who downplays the perceived ‘level’ of friendship whilst asserting his role as an advisor on the man’s sexual health. In this extract, PrEP use is also juxtaposed with what are represented as esoteric practices such as fetishism and group sex. Also central to this construction is the idea of ‘PrEP etiquette’ where users appear to be expected to take the drug discreetly. Some participants viewed men in larger gay centres such as London and Birmingham as having riskier and more sexually adventurous lifestyles making comments such as ‘in London you’re going need this (PrEP)’ (P1 HIV− Group 1). Xenophobic comments were also made about both the number of gay men ‘from abroad’ on the gay scene and the high HIV rates of GMSM in London cementing a sense of elevated risk and louche behaviour in other cities from which the ‘provinciality’ of Leicester offered protection.

Several of the participants argued that ‘certain sorts of gay men’ would be using PrEP – and that these were typically men with ‘irresponsible’ lifestyles that suggested a low likelihood of managing appropriate levels of adherence. Conversely, some believed that PrEP users who preferred drug-based rather than behavioural strategies for HIV prevention would be more likely to be using recreational drugs and that this may affect adherence or the effectiveness of the drug:

I think it goes back to that whole responsibility thing and what have you. And those people haven’t the responsibility to carry on taking the PrEP pill. (P9 HIV− Group 2)

P7: Another thing about the Chemsex and PrEP, I mean if you’re under the influence of drugs and don’t have any inhibitions, will you be, I mean would you be taking the drug.

P11: Would it even still work? (Group 2, both participants HIV−)

In these extracts, we see further evidence of the ‘othering’ of PrEP users who are typified as having a reckless disposition, and therefore constituting a risk to themselves and others. The content and communication of the talk here appears to provide evidence of concerns that behaviours such as PrEP use and Chemsex (which might be seen as ‘advertising’ hedonist and ‘irresponsible’ gay lifestyles) have the potential to threaten the acceptance of GMSM in contemporary neoliberal British society. Thus, showing awareness that advances in LGBTQ rights may be more fragile and contingent than they appear, alongside a recognition that the meanings and limits of acceptable gay/queer sexual citizenship continue to be heavily scrutinised and potentially constrained (Gusmano, 2017).

Inextricably linked to concerns about the consequences for how gay men on how PrEP is represented, several participants discussed the media – as a mechanism for information and meaning-making:

P2: The general consensus from the mainstream media… particularly the red-top papers is that… it’s an expensive means of the NHS for allowing gay men to have reckless- unprotected sex without protecting themselves, that it’s by all means, it’s nothing like one-hundred percent successful actually it’s just a means of financing peoples’ promiscuousness.

P5: From the studies that I’ve seen, there’s only two people in the world so far who have been infected with HIV whilst taking that tablet, and they were found to be not taking it properly. That actually pretty high rate of protection.

P6: Yeah

P2: Okay but that’s not at all what comes across in mainstream media.
P4: Because it’s alright for straight people to have promiscuous sex and babies, but it’s not alright for gay people to. (Group 1, all participants HIV−)

These data also show concerns around how representations of ‘irresponsible’ and ‘lazy’ gay men taking medication can reinforce prejudicial coverage of gay communities, especially in tabloid (‘red top’) newspapers. Not only does this involve painting those GMSM who do not follow heteronormative norms of monogamy (and potentially the wider GMSM community) in a negative light, this coverage also casts doubt on the efficacy of the drug and implies a diversion of valuable resources from other ‘more deserving’ health causes for government funding. Although here participants appear to resist these negative representations and recognised the double standards of reporting, as we have seen, other participants appeared to accept these views, and showed disapproval and distancing from men who were overt in their PrEP use. In participant 2’s contribution, we see some indecision on whether to heed media reports that the drug is not fully effective. This relates to issues around distrust of both PrEP itself and its implementation, which will be discussed further below.

‘There’s a culture of anti-trust’: prep, stigma and the interpersonal politics of HIV disclosure

PrEP was talked about in rather different ways by men in the HIV+ and HIV− groups especially when discussions moved from wider representations of PrEP users to PrEP use in specific sexual scenarios where one man is HIV+ and the other is HIV−. Central to understanding, the way in which the HIV+ men talked about these challenges was the high level of stigma they experienced within local communities – especially when discussing potential hook-ups with men via sociosexual apps such as ‘Scruff’ and ‘Grindr’ (which most of the participants used) if they disclosed their HIV status. One participant found the local community to be markedly less accepting of being HIV+ than in Brighton where he had previously lived:

*HIV is like the plague here. I absolutely hate it now. Just makes you feel shit.* (Participant 13, HIV+ Group 3)

Within this landscape, HIV+ men in this group proffered that PrEP had potential to ‘re-balance the power’ and be ‘liberating’ for HIV+ men having sex with HIV− men in what they called ‘the marketplace’ of casual sex. Most HIV+ men saw PrEP as negating the need to disclose being seropositive in such encounters, shifting perceived responsibility onto the HIV− partner in maintaining his sero-negativity. Such views were also strongly influenced by stigma from HIV− men and experiences of what the men found to be controlling and unempathetic views from healthcare professionals who they felt, as demonstrated in other research (see Race, 2016), had little understanding of the intimacy and pleasure of gay men’s (unprotected) sex and simply repeated monolithic messages around condom use or abstinence:

P14: If we don’t develop a way to use PrEP within the (gay) community, we fall back to the person with HIV is always the problem. They need to have their activity controlled and we’re still in the same situation that in an instance where you have sex with somebody by default it falls on you being the HIV positive person to have all the responsibility, all the accountability.

P18: Cause you get all the bumph about the legal implications.

P14: for PrEP to be successful, the education has to fall on the other side… if you are going to be a little tart you make a decision like do I fancy, well… I can put my legs in the air and I just don’t care. I’d like to see it moving away from being the HIV positive person’s problem. if both people are educated about what PrEP’s role is it means you can engage in the sort of sex you want to have – the best sex ever – with the person you want to do it with the minimum amount of risks and hang-ups. That can be quite liberating for the HIV positive person because I don’t have to have sex with guilt and for the negative person it is a safety net. If someone said to me I’m taking PrEP I would say great, that’s excellent you’re a bit informed, we can be as dirty as you want to be.
Various elements of this extract are important to note. Consistently with many recent findings, ‘bareback’ sex was almost universally represented by the men in the group as ‘superior sex’ to anal sex where condoms are used recognising some of the interference of condoms to both intimacy and eroticism that have been noted in research (Adam, Husbands, Murray, & Maxwell, 2005; Avila, 2014). As observed by Race, effective health promotion understands that pleasure and health do not need to ‘stand in opposition to each other’ and a key part of PrEP’s appeal is because it integrates effective HIV prevention with what many GMSM view as heightened embodied pleasure (Race, 2010, 2016). Second, PrEP use was seen by the majority as synonymous with making condoms redundant. This is significant as one of the main concerns around PrEP has been ‘condom migration’ or ‘risk compensation’ although this has not always been seen in research findings (Auerbach & Hoppe, 2015). However, in our study, only one participant discussed using PrEP as an ‘extra’ protection to routine condom use – which is the central message of modern PrEP health promotion (Hill, Bak, VandeVusse, & Rosentel, 2017). Our participants often uncritically endorsed ideas around healthism (acceptance of a moral obligation to protect your health for your own good and that of society) but appeared to interpret this as being achievable through either condoms or PrEP or TasP (some of the HIV+ men described themselves as ‘undetectable’) – not both in conjunction.

Although the HIV+ men described PrEP use in bareback sex encounters as mutually beneficial, men in both of the HIV− groups took a different perspective and felt that HIV+ men should disclose their serostatus to allow them to make an informed choice about whether or not, and how to have sex. In this context, PrEP was viewed warily with several participants in the HIV− groups citing incidents of HIV+ men representing themselves as taking PrEP and therefore as being HIV negative:

'I know a person who is HIV positive because he told my friend many years ago, and my friend's got a screenshot, was like "oh my God look at this" and it's his profile on Grindr and it says I'm on PrEP. See he's lying to people and I think that's just awful and I just think that's gonna happen.' (P8, HIV− Group 2)

For these participants, the provision of drugs that were previously limited to HIV treatment allows an opportunity for HIV+ men to misrepresent themselves as HIV− and potentially highlights issues in how PrEP and TasP are both understood and communicated. These findings suggest significant concerns about how men who are having sex with men manage disclosure and the opportunity that PrEP can afford GMSM for engaging in the identity-protection strategy of feigning membership of a group that one is not actually a member. It also recognises residual feelings of suspicion and hostility that are evident within HIV+ and HIV− GMSM communities.

Other participants also recognised that these challenges around sexual communication and decision-making, whilst coloured by PrEP, are not solely attributable to it.

'There's a culture of antitrust coming through. And how can you make a call on whose trustworthy or not? Because it isn't a call about good or bad people, it's just about people making decisions in the moment. And is having PrEP helping the situation or making it worse? I don't know.' (P9, HIV− Group 2)

These data taken overall are concerning because they imply that PrEP may actually legitimise HIV+ and HIV− men avoiding meaningful discussions about sex which threatens not only sexual health but also potentially psychological well-being and the development of self-efficacy skills in negotiating sex.

‘I’m still suspicious about it’: discourses of doubt and distrust

Although all participants generally welcomed PrEP, most of the men expressed significant concerns concerning its safety and possible side effects. Several participants believed that demand for PrEP was being fuelled by both a small group of activists who wanted to ‘abandon’ condom use and by drug companies seeking financial gain. These views are similar to those noted in a recent American study in which participants viewed the motives of ‘Big Pharma’ with scepticism, arguing that HIV
prevention was becoming commodified by pharmaceutical companies who valued profits over HIV prevention (Thomann, Grosso, Zapata, & Chiasson, 2018).

As noted above, few of our HIV− participants had previously used PrEP and most seemed reticent about using it in the future. Many felt that ‘social media activism’ had ‘hyped’ a demand for PrEP from the GMSM community that they did not (yet) want to be part of:

P7: It can be irresponsible. It is something that will change the culture of gay sex, it will change the culture of how they behave and you know, right now it’s just touching the edges but in 10 years- there’ll be a complete shift, potentially if it goes mainstream. It goes, actually everyone’s going around getting antibiotics every 2 weeks because they’ve got gonorrhoea or whatever. But that’s okay because just take some antibiotics, whereas HIV we’re all cool.

P10: I don’t understand the science. Will HIV find a way to get around it? I don’t know. Then suddenly we’ll have an epidemic again.

P11: And is it one-hundred percent? Or is there a small chance that it is not that effective?

P12: Again, that’s kind of the whole social media thing, the way it’s kind of being sold is-

P7: There’s this glorious pill

P12: Exactly!

This extract illustrates a concern that PrEP is being prematurely endorsed and ‘celebrated’ by sections of the GMSM community. It is also noteworthy that participant 7 uses the third person pronoun (‘how they behave’) possibly to distance himself from ‘the culture of gay sex’, thereby protecting his own sense of identity.

Whilst some participants were dubious about its efficacy, most accepted that PrEP was effective in preventing HIV but felt that taking medication in the absence of illness could cause unnecessary harm:

P8: But I would be concerned about what you actually put into your body. I would be a bit worried about well, do they know what will happen in 10 years if you’ve been taking that drug for 10 years?

P10: Yeah side effects (...) I’m very suspicious about anything coming from the pharmaceutical industry. As you say, no one knows how it’s going to affect you in 10 years’ time. So yeah, I’m suspicious about it at the same time.

P9: Yeah. You say that about those drugs though. How long was Viagra trialled before it was rolled out?

P10: I think there’s a difference between a trial and a prevention. With this, I just think wow, what’s that doing to your body? If that’s protecting you against HIV, which is a really nasty virus, how’s it doing that, you know?

In this extract, a number of problems are voiced. Participants raised concerns about the potential long-term physical effects of the drug and reasoned that, in order to prevent HIV which was characterized as ‘really nasty’, the medication must be very powerful and thus potentially harmful. These data suggest a deep level of anxiety over a cumulative toxicity building up inside the body especially in the absence of longer-term evidence. Interestingly the HIV− partner in the sero-discordant couple argued that PrEP would be ‘redundant’ provided that his partner’s viral load remained ‘undetectable’, voicing concerns that ‘it hammers your kidneys forever’ and ‘there’s no long-term data over what it’s doing to your body’. (P17, HIV−, Group 3)

Some participants believed that there could be pressure from peers and healthcare professionals to take PrEP. They resisted the ‘liberation narrative’ arguing instead that wider availability and endorsement of PrEP could threaten personal codes of safer sex:

Ok so PrEP is a game-changer but for me, everything has to be taken with caution… what life style do I want to lead? I met… people who are very happy with having unprotected sex and there was a time that I think I was slowly getting onto that slippery slope. There was a time where I thought, you really want to get into PrEP? But then there was a time where I thought I have consciously made some life decisions where I don’t want to lead a particular life that I decided not to have it because for me personally, it would have given me a license to be a lot more relaxed, which I don’t want. (Participant 2, HIV−, Group 1)
Discussion

This qualitative study identifies the complexity and uncertainty in accounts of PrEP from GMSM living in Leicester. Participants expressed antithetical views about PrEP, juxtaposing benefits and challenges but also recognising that representations were contingent on both individual perspectives and cultural constructions within and beyond GMSM communities. The extent to whether or how PrEP use represented ‘responsible’ sexual conduct was debated in all groups with different views, most typically between HIV+ and HIV− men. Further paradoxical representations for PrEP were observable in participants’ talk – notably the potential for PrEP to both enhance and/or impair physical health and to challenge and/or consolidate homophobic representations of gay men.

Ambivalence about the ascribed meanings of PrEP among GMSM is echoed in recent research in the field with a tendency to shame PrEP users and to voice concerns about side effects of the medication (Jaspal & Daramillas, 2016) and the perceived commodification of HIV prevention (Young et al., 2016). Jaspal and Nerlich (2016) have observed how wider representations of PrEP are contradictory with PrEP being heralded as both a ‘wonder drug’ ultimately capable of minimising, even eradicating HIV, and as a ‘party drug’ wherein demand from GMSM represents another component of a hedonistic lifestyle, a ‘reluctant object’ which according to Race (2015) evokes associations with the excluded identity of the ‘rampant homosexual’. Our findings show that how those views are reflected and debated within different components of the GMSM community in Leicester.

Although we claim neither saturation nor generalisability of the findings, there appear to be several potentially useful implications of public health policy and provision for GMSM locally and nationally. Significant findings of this study include the continuing spectre of HIV stigma within GMSM communities that led many of our HIV+ participants not to disclose their status in casual sexual encounters, and the poor PrEP literacy exhibited by many of our participants. There is also clearly a continued need for interventions for GMSM in relation to self-efficacy skills in negotiating and practising sex in casual sexual encounters, and arguably a re-eroticisation of condom use (Philpott, Knerr, & Boydell, 2006) to communicate that condoms are compatible rather than antithetical with both PrEP and sexual pleasure.

However, as touched upon in theme one, there remain wider challenges for those involved in the development and delivery of public health strategies and policies for GMSM (Race, 2015; Race, Lea, Murphy, & Pienaar, 2017). It may be tempting for public health policymakers to adopt an unproblematic neoliberal approach to understanding GMSM and the lives they believe they wish to live. However, those developing interventions need to be cognisant of how public health policies emanate from heteronormative definitions of risk, responsibility and health behaviour (Auerbach & Hoppe, 2015; Keogh, 2017; Race, 2016). An irony of the significant social and civil changes experienced by LGBTQ people in Western countries in recent years, especially around marriage and parenting rights, is the presumption that gay men want to become ‘good gay citizens’ and adopt ‘homonormative’ versions of lifestyles most heterosexuals are seen to aspire to (Brisson & Nguyen, 2017; Brown, 2012). Those who do not wish to become monogamously partnered and form substance-free nuclear families, and wish to engage in drug-taking and/or casual bareback sex are automatically positioned as transgressive and in need of surveillance, intervention and/or control.

This superficial monothematic (im)moralisation of PrEP, alongside the association with notions of individual and collective irresponsibility (Keogh, 2017), ignores ideas of intimacy, assertions of erotic liberation, whilst subsequently also excluding GMSM that are not considered ‘high risk’ by public health bodies (Race, 2016). Such dichotomies stifle dialogue between those developing public health initiatives for GMSM and the intended ‘recipients’. Hence, there is a need to consider more holistic understandings of gay sex and drug-taking by GMSM. Paradoxically, PrEP is a form of HIV prevention method that makes drug-taking a quotidian habit whilst two significant public health concerns for GMSM are substance abuse and Chemsex (Bourne, Reid, Hickson, Torres-Rueda, & Weatherburn, 2015; Race et al. 2017).
Conducting this study in Leicester with its significantly higher representations of both Black and Minority Ethnic (BME) individuals, and men from a lower socio-economic status, helps expand the spectrum of voices informing PrEP initiatives. Usually, Public Health initiatives privilege the views of white, middle-class gay men when it is poorer and GMSM from black and minority ethnic groups who carry the greatest burden of inequality and poor health in the UK (Brown, 2012; Brown et al., 2018). Many GMSM generally and BME men in particular have become alienated from public health interventions and the false dichotomisation of GMSM into competing (for financial and social capital) bipolarities based on HIV status, and sexual responsibility and morality should be challenged in designing interventions (Race, 2015).

Overall our participants viewed PrEP cautiously with little evidence of PrEP activism seen in higher profile LGBT centres in the UK. The findings of this study demonstrate several potential barriers to the potential uptake of PrEP and there is a need to enhance understanding of PrEP amongst GMSM who may be under-educated or misinformed about this tool. Moreover, more needs to be done to challenge the prejudice surrounding PrEP in order for potential users to make choices which are not influenced by shaming and stigmatisation. Our findings can begin to inform the development of culturally informed local interventions, as well as lobbying for the funds required for implementation. Currently, across the United Kingdom, austerity measures threaten such community health initiatives resulting in interventions which are often rudimentary, decontextualised and reductionist (Blue, Shove, Carmona, & Kelly, 2016).

In conclusion, this study shows that the ways men in Leicester make sense of PrEP are multifaceted and may be distorted by misinformation and stigma. The publication of data on the safety of PrEP in lay language are paramount in alleviating some of the concerns men have about PrEP use and may help some of those HIV– men who are having high-risk sex make better informed decisions about how and whether to incorporate a PrEP regime. Further research and evaluation of interventions will be required to understand the ongoing challenges faced by those in public health and GMSM themselves and to facilitate how PrEP can become a key part of HIV prevention.

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