The workings of Pre-Exposure Prophylaxis (PrEP) citizenship amongst queer men in Denmark

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Abstract

In 2019, oral Pre-Exposure Prophylaxis (PrEP), a HIV prevention pill, was made available for ‘at-risk’ populations in Denmark, with uptake primarily seen amongst men who have sex with men. While PrEP has revolutionised HIV prevention by simultaneously providing sexual freedom and protection from HIV, it is accompanied by firm medical and social surveillance, through which, some commentators argue, PrEP citizenships are produced. This article draws on visual ethnographic data to explore how PrEP users in Denmark experience and reflect on the types of ‘work’ involved with, and moralities arising from, this PrEP citizenship. We argue that PrEP citizenship is contingent on the resources and abilities of individuals to proactively engage with this ‘work’ and balance the moral ambiguities of PrEP in relation to both local communities and their obligations concerning the Danish welfare state.

KEYWORDS: Pre-Exposure Prophylaxis, PrEP Citizenship, Biocitizenship, HIV prevention, Queer healthcare
Background and introduction

Oral Pre-Exposure Prophylaxis (PrEP) for HIV prevention was first approved by the US Food and Drug Administration (FDA) in July 2012. Since 2015 the World Health Organization (WHO) has recommended PrEP to be offered as a supplement to condom use for “people at substantial risk of HIV infection” (World Health Organization 2016, 53). Whereas condom use was previously seen as the main way to prevent HIV infection, the PrEP pill has been recently shown to effectively protect its users against infection when taken as prescribed. PrEP has in many ways reconfigured the sociality and materiality of HIV prevention. Being a biomedical prevention method, PrEP has heightened the personal responsibility and control of HIV prevention by shifting certain prevention practices away “from the community into the clinic” (Bernays et al. 2021, 8). PrEP has also produced and mediated new identities, subjectivities, and intimacies (Dean 2015; Guta et al. 2021; Bennett 2018). One example of this is how PrEP has been viewed as blurring the lines between the seronegative and seropositive binary, partly because PrEP is the same antiretroviral drug as that taken by people living with HIV (Martinez-Lacabe 2019). As PrEP is implemented as a prescription drug in many settings, access to PrEP is often reliant on medical gatekeepers, whose approval relies on medical eligibility criteria and definitions of being ‘at-risk’. PrEP thus has the potential to introduce new social experiences and practices with regard to HIV prevention. This is captured by a growing body of research. From the beginning, PrEP has sparked disputes and debates regarding individual obligation, collective responsibility and ‘safe sex’ ethics (Bennett 2018; Holt et al. 2019). While the evidence has cemented the efficacy of PrEP and its value in combating the spread of HIV, the extent to which PrEP promotes ‘safe sex’ has been contested. PrEP has been opposed by both medical and queer communities with claims of how PrEP might increase the spread of other sexually transmitted infections, an argument which Bennett (2018) argues is tied to traditional discourses of sexual ‘respectability’. Another critique focuses on the perspective of PrEP as a new form of biopolitical control. Here, rejecting PrEP can be considered a form of political resistance against the historical disciplining of homosexuality (Dean 2015). Dean (2015, 11) refers to how “biopolitical side effects” should always be considered as part of any broad pharmaceutical intervention and that such technologies are not silent tools in sexual encounters, but active mediators of how sex is experienced and practiced. Although medicines such as PrEP can be seen and experienced as sexually emancipatory, at the same time they require specific levels of medical categorising, monitoring and surveillance.

Against this background, and in the interest of understanding what PrEP requires of queer men either taking or considering taking PrEP, we analyse ethnographic material through the lens of PrEP citizenship, drawing on the theory of biological citizenship (Rose and Novas 2005; Orne and Gall 2019; Petryna 2004). Specifically, we examine what it takes to be given PrEP, detailing the work and moralities that PrEP users, as PrEP citizens, need to carefully and skillfully navigate.

PrEP Citizenship

To examine the work involved in navigating access and moralities related to PrEP, we apply the concept of PrEP citizenship. This concept has its roots in the theory of biological citizenship (Petryna 2004; Rose and Novas 2005; Heinemann 2016) which is concerned with how biological or medical indicators define certain citizens with specific rights, ethics, regulations, and obligations. In the following section we outline how citizenship theories have been developed to study health and illness, how they have been applied in the context of HIV, AIDS, and PrEP, and how they contribute to our analysis in this paper.

Biological citizenship was first introduced as a concept by Petryna (2004) who showed how the consequences of the Chernobyl catastrophe in USSR, in interplay with the economic transition to a market economy, brought about a new “political economy of illness” (2004, 256) which...
people impaired by the disaster had to navigate in order to claim compensation. The concept was further elaborated by Rose and Novas (2005) who highlighted how citizenships are produced in active enactment by individuals as they engage in self-monitoring or self-education about their bodies, or participate in activism centered around their diagnoses or biological conditions. The political dimension of biological citizenship was furthermore pointed out by Heath et al. (2007), who emphasised how public awareness and articulation of genetic dimensions of illness have facilitated new mobilisations among patients with rare genetic diseases who organise and engage politically in activism to advocate for their rights. Biological citizenships do not only exist in the context of disease, but have also been applied in analysis of constructions of ‘at-risk’ groups, who may enrol onto lifelong surveillance trajectories with the purpose of remaining healthy as illuminated by Heinsen et al. (2022), in their study about people living with elevated risk of colorectal cancer. In his work on pharmaceutical citizenship, Ecks (2022; 2005) draws attention to the role of the global pharmaceutical industry when he argues that commercial interests in expanding markets shape a reconfig-uration of social understandings of marginalisa-
tion (in the shape of depression), by promoting anti depressants as a pharmaceutical solution to it. Jauho and Helén (2022) show how Finland as a Nordic welfare state forms a specific context for citizenship projects, in which vitality plays a central role. At the same time, healthcare services have historically been delivered and prioritised by a principle of “differentiation by vitality” (Jauho and Helén 2022, 9), by which the less vital (deviant or disabled) have been deemed eligible for surveillance as well as care. Since their resources are limited, welfare states must prioritise how to uphold vitality amongst citizens in order to maintain a productive population.

Following on from these concepts, the citizenship framework may consider how global and local political arenas, clinical encounters and social identity are transformed in relation to technoscience and biomedicine. While becoming part of a patient or ‘at-risk’ group, a person can claim certain rights for treatment and care, but in turn is also assigned the obligations and responsibilities related to their status as ‘citizen’.

In the context of HIV and AIDS, the concept of citizenship has been applied to explore how economic structures and biomedical possibilities shape how people engage in treatment and prevention technologies. Nguyen et al. (2007; 2007) elaborate on how efforts to become ‘part of the group’ for HIV patients in national contexts with sparse treatment resources, are not limited to simply having a positive test, but also entail fitting into the identity of the right candidate for treatment. They examine how people undergoing HIV treatment become therapeutic citizens who must balance the rights and obligations inherent in the role of an adherent HIV patient. Nguyen points to how strategies of local triages to prioritise access to limited treatment have produced citizens’ survival tactics, such as “telling the good story” in order to be chosen as lucky ones (2007, 133). In their study from Uganda, Russel et al. (2016) demonstrate how people living with HIV categorise themselves as groups of ‘responsible’ citizens by engaging in HIV education, self-management and correct adherence to medicine. Young et al. (2019) point to the repercussions of pharmaceutical developments within HIV citizenships. The authors show how HIV citizenships, in the context of treatment as prevention (TasP), encompass not only self-monitoring and self-care, but also responsibility for others “on a political, bodily and even molecular level.” (Young et al. 2019, 14).

The emphasis on responsibility is also prevalent in Epstein’s work on biosexual citizenship (2018). He points to how, within biosexual citizenship, sexual rights are deeply tied to ‘sexual responsibility’, referring to the idea that everyone is obliged to make informed choices and manage their own health, in order to have sexual autonomy. Epstein (2018, 38-39) argues that the appearance of ‘LGBT healthcare’ has introduced a new kind of governing project, offering inclusion of queer sexuality in biomedicine, albeit within an authoritative framework that emphasises responsibility rather than pleasure. Within the context of PrEP, Race (2016) has pointed to established science’s
disinterest in sex and pleasure, in spite of its evident relevance for how it is used (Mabire et al., 2019). Similarly, the tension between individual desire and the collective “Ethics of Ending AIDS” (2018, 103) is discussed by Bennett who refers to PrEP as a kind of ”chronic citizenship”. Bennett points to how the individual and intimate praxis of taking PrEP has the potential to dismantle the HIV pandemic and reshape the social understanding of HIV/AIDS if implemented sufficiently.

Orne and Gall (2019) use the term ‘PrEP citizenship’ in their empirical analysis of the experiences of USA-based queer men. They point to how, with the uptake of PrEP, a person launches into being problematised as a biomedical site for intervention, including not only behaviour (such as rules for adherence) and biomedical surveillance (such as testing for Sexually Transmitted Infections (STIs)), as well as obligations to contribute to research data, but also extensive surveillance of the self and others. In return for the surveillance practices, the authors argue, PrEP users gain access to symbolic and material resources of identity, safety, sexual community, and healthcare. They furthermore highlight how PrEP citizenship is not only relevant for users of PrEP, but also for non-users as they are now categorised and exposed socially as such (Orne and Gall 2019). Thus, PrEP enforces biosocial categories related to its ‘at-risk’ target group as well as biosocial distinctions between the ones who have access and choose to use PrEP versus those who do not. These new biosocialities have been examined by Girard et al (2019) who in a study amongst queer men in Canada highlight how categorisation processes related to the use of PrEP involve negotiations of responsibility and risk.

In this paper we build our understanding of PrEP citizenship on the conceptualisations outlined above. We consider PrEP citizenship to have both individual and collective dimensions, in that PrEP mediates how people understand and measure their own bodies, and at the same time organise and live their lives based on medical categorisations, such as being classified as ‘at-risk’. From this perspective we explore how PrEP users engage in the ‘work’ of PrEP citizenship, including how memberships of the ‘group’ of PrEP citizenship are constricted and facilitated, and how tensions and intersections between private and public interests shape the experiences of PrEP. Our paper will contribute to a wider understanding of how PrEP users actively and tactically engage with surveillance regimes and categorisations, in the specific context of a Nordic welfare state such as Denmark where PrEP is available at no private cost, yet only through a few strictly controlled channels. Furthermore, we contribute with new knowledge to the wider health citizenship literature by drawing attention to the particularity of treatment-as-prevention pharmaceuticals, prescribed based on self-reported, behavioural criteria.

The Danish context

In 2017, the Danish Health Authority recommended the implementation of PrEP as a “pharmaceuticalal supplement to existing prevention efforts which should remain focused on safe sex, early detection and effective treatment” (Danish Health Authority 2017). At this time, the availability and acceptance of PrEP spread rapidly in other European countries, though not without contentious debate and discussion around inclusion criteria, cost, efficacy and side effects. PrEP officially became available through the national health services in Denmark in 2019. In 2020, 1,180 individuals in Denmark were on PrEP (Region Syddanmark 2020), a number that reached 2,000 in 2022 (Primdahl et al. 2022). It can be assumed that an additional, but unknown, number of people buy PrEP from unauthorised providers online.

In Denmark, criteria for PrEP include being HIV-negative, being a man or a trans person who has sex with men, having had unprotected anal intercourse with multiple male partners within the last 12 weeks, or having contracted syphilis, chlamydia, or gonorrhea within the last 24 weeks. When PrEP was first implemented the age limit according to guidelines was 18 years old; however this was later changed to 15 years old (Region Syddanmark 2020). Furthermore, the person must “be prepared to follow current guidelines
PrEP can only be prescribed by a specialist in infectious medicine, meaning that consultations take place at regional hospitals with an infectious disease department, or at one of five urban clinics (‘Checkpoints’) run by AIDS Fondet, a Danish non-governmental organisation which collaborates with doctors from the infectious disease departments. PrEP initiation thus requires either a referral from a general practitioner to access the infectious disease department or a visit to a ‘Checkpoint’ clinic. At these locations for PrEP assessment and initiation, potential users meet healthcare providers who run clinical tests and inquire about sexual behaviour. In addition to liver and kidney tests, potential PrEP users are tested for HIV, chlamydia, gonorrhea, and syphilis. Once PrEP is prescribed, it is provided for free by the public healthcare system. While other prescription medications are distributed to pharmacies where patients or users pick them up, PrEP is handed out at control visits at the clinic or hospital once every three or six months. At the control visits, certain tests are repeated and healthcare providers continually assess whether or not a person still belongs to the ‘at-risk’ group and qualifies for PrEP (Danske Regioner 2019). In Denmark, PrEP cannot be bought legally outside the public healthcare system. Thus, PrEP provision may be seen as a pertinent example of the Danish welfare state's principle of providing free healthcare for those ‘at-risk’, while tightly managing how they fulfil ‘at-risk’ criteria as well as the surveillance obligations inscribed in the PrEP programme.

Methods

This paper is based on a qualitative Photovoice and interview study of user perspectives on PrEP in Denmark. 16 queer men residing in Denmark participated in the study by either producing Photovoice material, or participating in interviews with the first author, or both. Two of the participants self-identified as trans and gender-fluid men respectively, while 14 self-identified as cis men. 10 of the participants were Danish and the remaining six were of Greenlandic, Swedish, Slovak, Venezuelan, Chinese and Canadian origin but resided in Denmark. Most participants were younger, aged 21-42, except for one who was 65 years old. The participants lived in bigger cities, had mostly completed continuous education and all were either employed or studying. Thus, it is important to note that this study covers just a small corner of PrEP experience, because issues related to income, geographical location, race, and gender identity did not appear as challenges for most of the participants.

The study was carried out with a participatory approach by the involvement of a co-researcher group, which included two PrEP users as well as two healthcare providers who work with PrEP. The co-researcher group was involved in recruiting participants, planning the research design, and preparing interview guides, as well as in analytical discussions.

Photovoice is a visual qualitative research method that invites people to use photography as a means to identify, illustrate and make suggestions for the improvement of issues that matter to them (Wang et al. 1998). In this study, participants were invited to take six photographs depicting their experiences and perceptions of PrEP. Participants were also asked to write short explanatory texts for each photo they took. The Photovoice material, together with the semi-structured qualitative interviews, were then coded and analysed.

The 16 participants for the study were recruited through several channels. The members of the co-researcher group shared information about the study in their network, and healthcare staff contributed to the recruitment of participants by sharing information about the study. In addition, information about the study was shared on social media, including relevant Facebook pages as well as via a paid advertisement on Instagram that was specifically aimed at the target group. All interested participants were thoroughly informed about the study and they provided written informed consent. The Photovoice component was introduced via Zoom meetings where participants could remain anonymous. It was also possible to have a private introduction with the researcher, if that
suited the participants better. The participants had two weeks to take the pictures and write up the stories they represented. The material was then shared with the research team, who stored it securely, in accordance with local data protection regulations. The semi-structured interviews were conducted after the participants had produced the Photovoice material. The interviews lasted between 45 and 75 minutes. Some were carried out in person, but most were done via Zoom or Teams due to COVID-19 recommendations. All the material was transcribed, coded, and analysed thematically in Nvivo 12. In the following sections we examine and discuss how PrEP citizenship is an ongoing process, involving different types of work as the participants negotiate and navigate moralities.

‘Working out’ the system to access PrEP: Knowledge and information

To enter PrEP citizenship and gain access to PrEP, a person must be deemed an eligible candidate for the treatment. Participants in this study gained access to PrEP by adopting different tactics to gain eligibility. The first step in this process was to know about PrEP and its availability. According to the participants, people hear about PrEP primarily through social networks and online, and many reported having engaged in active self-education to gain sufficient knowledge. Although a few participants described being recommended PrEP by their general practitioner, several of the participants expressed a general lack of knowledge and awareness about PrEP amongst healthcare personnel. Charles, one of our participants interested in starting PrEP, described how information about where and how to access PrEP was unclear and inconsistent:

> The information available to me, about the actual, practical logistics... now, I’ve seen in one source, that I have to go to a specialty clinic for it to be assessed and reviewed. And in another source, I saw that I could get it via my own family doctor. The anecdotal comments of people I have met in the past year who are on PrEP, have said that they got it from their family doctor very, very easily. (...) So, now, I feel that my knowledge of the practical logistics of requesting assessment for PrEP and then getting PrEP is a little bit... up in the air. I simply don’t see any clarity in the information, I have received. (Charles, 65 years old.)

Like Charles, several participants have been confused about the process of accessing PrEP. This may be attributed to the fact that there is more than one pathway to PrEP and insufficient awareness of what ‘getting it via a general practitioner’ entails (i.e., only a referral). Several of our participants spoke about how they had to educate their GP about PrEP and have helped them look it up online. Due to confusion amongst potential PrEP users and gatekeepers, it seems to be a requirement for PrEP users, and those interested in PrEP, to become spokespersons and educators for PrEP. Thus, proactive engagement in self-education, access to social network resources, and knowledge about healthcare systems are important components of active PrEP citizenship, and for many a prerequisite to gaining access. This kind of ‘working out’ the system, supported by the option of seeking information and tactical advice on the internet, can be seen as the first task of PrEP citizenship. Interestingly, much of the thorough online information about PrEP in Denmark is available through civil society organisations such as the Danish AIDS Foundation’s website. As also noted by Heath (2007), the internet facilitates international and local alliances, advocacy and the active lay use of biomedical knowledge, as we see in this case, in which alliances are formed between potential users and civil society organisations to spread information about PrEP.

Identifying ‘what works’ to access PrEP: Choosing the right tactics

Once the initial conversation about PrEP has begun, the next step is to be categorised as being within the target group. Amongst the small group
of participants in our study, the rigidity of criteria for PrEP is interpreted differently, depending on the clinic and the practitioners. Some are told by their GP after a lengthy talk about their sexual history that they do not meet the criteria, and therefore cannot get a referral for a PrEP consultation at an infectious disease clinic, while others receive a referral without having to say anything about their sexuality. Many things may be factors here, but the newness of PrEP may be one of the contributing factors to this inconsistency. Petryna (2004) observed in her study of the aftermath of the Chernobyl disaster that “…a new political, economic, and moral arena had been thrown open owing to the absence of consistent evaluative criteria.” (2004, 255), pointing to how criteria for care were being implemented while public debate continued about their validity. In the case of PrEP in Denmark, although official guidelines are in place, the level of awareness of these, or GPs’ own norm values or perspectives on sexual minorities, may shape how easy or difficult it is for people to access a referral letter.

A few participants described how they had to adopt certain tactics to gain access to PrEP, such as seeking PrEP from a Checkpoint community clinic after being rejected by their GP. One participant, Jose, explained how he was initially refused a referral letter from his GP because he stated that he did not engage in condomless sex. Keen to access PrEP, Jose went to a Checkpoint clinic, thinking carefully about what (not) to say. Finding Checkpoint to be a safe queer space, Jose felt comfortable telling the doctor that he was experimenting with chemsex, a practice that is seen to undermine consistent condom use, and which according to the Checkpoint doctor, qualified him for PrEP:

\begin{quote}
That of course prevented me from taking it for yeah quite a while, eh, until I decided to engage in chemsex basically (laughs). So that’s how I was finally approved to take it which is a little bit crazy if you think about it because okay well in order for you to take PrEP you have to take drugs, I mean that’s a little bit strange, no, but that’s how it happened. (Jose, 33 years old.)
\end{quote}

What puzzles Jose here is the mechanism by which being categorised as ‘of increased risk’ or liable to ‘irresponsible behaviour’ becomes a gateway to PrEP – accentuating the paradoxical nature of PrEP citizenships. While PrEP is experienced and understood by participants as a generally healthy and responsible choice for the individual and the community, being ‘at-risk’ is a prerequisite for access. For Jose, this meant disclosing his chemsex practices, while for most of the participants meeting the criteria meant being categorised as having had condomless sex within the last period.

‘Working’ the PrEP service delivery system: Performing vulnerability

While Jose’s account demonstrates how PrEP can be obtained by learning ‘what works’ in the PrEP system, several of our participants spoke about how they actively ‘work the system’ to access PrEP. Simply wishing or planning to have condomless sex in the future does not qualify someone for PrEP. In practice, however, PrEP prescriptions are obtained ahead of condomless sex by users who have the resources to know what it takes to qualify for PrEP. One participant, Christian, described his tactic for obtaining a PrEP prescription:

\begin{quote}
So, when I came to interview at... the hospital. We talked about it a bit and... And then to make sure I could get it, I just said... what they wanted to hear. That I had unprotected sex with a lot of people. And then I got it... (...) I don’t know, I think maybe I was a little... well, nervous that I would... wouldn’t get it, if I had... been a little more honest. Yeah, well, I didn’t know quite how much it would take to... to get it. (Christian, 26 years old.)
\end{quote}

Christian, like several other participants, wanted to make sure he qualified for PrEP by telling the narrative he knew the health professionals wanted to hear. It appears that inclusion in PrEP citizenship
The workings of Pre-Exposure Prophylaxis (PrEP) citizenship amongst queer men in Denmark requires both a mobilisation of resources (such as knowledge, time, navigation tactics and social networks) and an enactment of vulnerability, in order for someone to be prioritised by the providers as a cost-effective user. In terms of access, such demands may prevent some potential PrEP users from ‘working the system’. These apparent barriers show a discrepancy between public healthcare strategy, which aims to prioritize PrEP access for the most ‘at-risk’ and vulnerable groups, and how it is experienced by users in practice, even for the resourceful participants in this study, as something for which it is difficult to obtain a prescription.

‘Working with’ the PrEP service delivery system: Privileges and moral obligations

As described in the introduction, once a person has begun their PrEP use, they are obliged to participate in control visits every three or six months to receive their medication. Most of the participants in this study expressed gratitude for the regular control visits. The close contact with healthcare providers was experienced as a reassurance by many of them. In addition, it made it easier for the participants to be tested for sexually transmitted diseases, since they did not have to book an appointment or sit in a queue at their GP or another clinic. Thus, being on PrEP can be experienced as having ‘entered the system’ in a privileged way, especially by virtue of having access to permanent and experienced staff with knowledge of sexual health. In the following Photovoice story (Photo 1), Christian describes how his PrEP citizenship provides him with access to regular testing in a safe space, which appears almost more important to him than the PrEP pills themselves.

I want to share this picture, to tell how happy I am to be tested regularly. Since starting PrEP, I’ve been tested for STDs every three months. In the approximately two years I have been tested regularly, the hospital has tested me positive for both chlamydia and gonorrhea twice. All four times I had no symptoms, and if I hadn’t been tested, I could have spread these diseases unknowingly. Plus, they could have had an impact on my physical health. In the Infectious Diseases Department, I feel that as a person I am not shamed when I come in to be tested for STDs. Unfortunately, I have not had this good feeling with my GP. The first time I was tested for STDs at my own GP, there were no major problems other than the fact that I have subsequently found out that I was not tested well enough - I had not been inoculated in all the places that I should...
have been. When I came in a few months later to be tested again, I felt shamed. My GP said it couldn't be right that I should already be tested again, and that I should be mindful of having safe sex. Just to be tested often and not feel embarrassed is reason enough to take PrEP. (Christian, 26 years old.)

For Christian, his entry into a “site for biomedical intervention” (Orne and Gall 2019), is experienced as a privilege he did not have before. Many of our participants mentioned how they had negative and unsafe experiences when seeking medical care to be tested. They experienced a lack of knowledge and competence of LGBT+ sexual health amongst healthcare providers, contributing to feelings of exclusion or shame. Inclusion into a PrEP regime, in which regular and competent testing is the norm, felt to many like a ‘privilege’, compared to the alternative.

Other participants reported how they experienced control visits as rigid and imposed surveillance. Though screening for STIs is not formally a legal requirement for obtaining PrEP, the perception amongst participants was that it was mandatory. In the following Photovoice story (photo 2), Mike describes how he experienced the control visits as his being made into a scientific object.

This picture is of a planned trip to Hvidovre Hospital. This is where I go every three months to get my medication - no exceptions. The Danish Medicines Agency has stipulated that the dispensing of medicines must take place from hospital infection medicine departments. Because even though my doctor can, in principle, take the tests necessary for me to be given my medicine, I have to take half a day off work to go to Hvidovre. And note that there are tests that are necessary - and then there are those that are kind of unnecessary but required before I can be treated. The ones that are not a medical reason to take, the ones that are not related to my medication, but are taken because as a PrEP user, I am being screened. I am a statistic. I am, in part, because a workgroup follows me and you - if you take PrEP. They will develop a common guide for targeting, dispensing practices and monitoring follow-up - with one goal in mind, to ensure the lowest cost-effective level of my treatment. So, despite meeting good, skilled and understanding nurses and doctors, I feel very much that I am part of a system, an object, rather than a human being whose health the system cares about. (Mike, 32 years old)

Mike does not consider screening for STIs other than HIV as “necessary” or directly relevant for his PrEP use, but rather as something that is part of his PrEP citizenship, to provide data for the general surveillance of the ‘at-risk’ population. This example demonstrates how the practices embedded in PrEP citizenship are carried out both in individual bodies, as well as in collective population, which echoes Rose and Novas’ (2005) concept of biological citizenship. In addition to experiencing control, the practicalities of visiting the hospital every three or six months are described as difficult and troublesome by many participants. Since control
visits must take place during hospital working hours, PrEP users must find ways to manage this within their work schedule. For those living further away, travel time may be an issue. While most participants in this study were working flexible hours in office jobs, and lived close to hospitals, several of them pointed out how the hospital visits would be impossible if they had jobs which required set working hours or if they were unable to disclose PrEP use to their line management. Mikkel feels “lucky” to be able to attend control visits and maintain his PrEP because he knows this might be more difficult for people in different work situations.

I think there are people who don’t have as, well, have as flexible jobs as I do. So, I feel quite lucky, but it can be difficult for others. (Mikkel, 26 years old.)

This reflection seems to be a symptom of a larger tendency in how the participants enact and experience their PrEP citizenships. Many participants articulated gratitude, and feelings of luck, and privilege, for accessing PrEP freely; none more so than participants with origins outside Denmark. This gratitude aspect adds yet another dimension to the complex negotiations of PrEP citizenship that we are examining in this paper. While feelings of gratitude present a positive angle on PrEP, it also seems to relate to specific dilemmas of eligibility and cost effectiveness that participants consider as part of their self-monitoring. Whether or not to discontinue PrEP is expressed as an ongoing dilemma for participants who are not sure if they are sexually active ‘enough’ to justify their PrEP use. For Holic, who has been using PrEP on and off while on a permanent prescription, this leads to moral predicaments.

...when I take it, I feel ‘oh I haven’t had unprotected sex for two months and I’ve been, you know, taking it every day, so why?’ Uh and then I feel almost like... like an obligation to have unprotected sex, like. (Holic, 32 years old.)

This monitoring of Holic’s own sexual practices has become part and parcel of his everyday life and work as a PrEP citizen. Holic is torn between continuing or discontinuing PrEP, in the context of reduced sexual activity and the work involved in getting a PrEP prescription. While Holic can offer little ‘white lies’ to healthcare providers and remain on PrEP without problems, he still faces the responsibility of monitoring his eligibility with the knowledge that he might ‘waste’ expensive drugs. Such dilemmas illustrate how PrEP citizenship is produced actively in interplay between institutional guidelines, moral economies, and the complexity of sexual pleasure and daily lives. The dilemma of when and how to stop taking PrEP accentuates how, in relation to PrEP, belonging to the ‘at-risk’ group is a dynamic status. In contrast to other ‘at-risk’ groups, such as groups defined by elevated genetic risks measured by standardised technoscientific tools (Heinsen et al. 2022), being ‘at-risk’ in relation to PrEP is defined by self-reported behaviour. This may put a particular pressure on PrEP users to monitor themselves to continuously judge whether they are still sufficiently ‘at-risk’.

‘Working for’ PrEP visibility: Articulation and activism

As mentioned above, the difficulties and ambivalences related to control visits is spoken of by participants as a potential barrier to access. Furthermore, the need for control visits may also force people to disclose their PrEP use to coworkers or family who are curious about why they have to visit the hospital. Participants describe how such conversations can be necessary in order to avoid misunderstandings, i.e., they do not want others to think that they are sick, but can also be experienced as involuntary disclosure of intimate information. Participants explain how conversations about PrEP, especially with people who have little knowledge about it, quickly become conversations about their sex lives. Bo, a gay trans man, explains how conversations about PrEP for him also entail taking on the work of breaking taboos:
Being transgender and having a sex life. I mean, it's incredibly taboo, especially when you're a trans man. Because you have some idea that trans men um... can't have sex. So not... their sex life doesn't exist. And you're not... well, it's very secretive, the whole thing. Um... And it's also internal in the environment. Which is a huge problem. So that's one of the things I'm working on a lot, to try to put it into words, to say... like everyone else, trans people have sex lives too. Yeah. So that's one of the things that I'm very activist about. (Bo, 21 years old)

As described by Bo, self-disclosure becomes an activist practice which is part of his PrEP citizenship. In contrast to other biosocial groups defined by genetic measurements or somatic diagnostics, the 'at-risk' group eligible for PrEP are classified by being open about these intimate details.

Participants articulate and disclose their PrEP use to varying extents. However, there seemed to be consensus amongst our participants that knowledge about PrEP should be spread and most of them expressed how they feel an obligation towards this collective goal. Many of the participants, who themselves have received information, support, and knowledge about PrEP through their social networks, expressed a strong feeling of passing this help on to other potential users. For this reason, dilemmas of who to tell, and how to tell them, about their PrEP use, and balancing this moral obligation to their own boundaries and privacy, are part of the participants' negotiations of how to be 'good' PrEP users. Dating appears to be a situation in which information and disclosure of PrEP is often shared. When it comes to intimate relationships, participants report how being on PrEP can provide them with specific kinds of sexual capital when potential sexual partners know that they are regularly tested and HIV negative. For some, their initial interest in PrEP was due to experiences of being rejected because they were not on PrEP. This underlines how PrEP's influx into dating apps and spaces is generating new hierarchies and identities, which have relevance for non-users who are not able to meet the 'new' standards for sexual practices. Being on PrEP entails engaging in educational and activist work based on continuously negotiated moral obligations. The fact that there seems to be an explicit aim for many of the participants to spread the word about PrEP, while the authorities seek to restrict PrEP to smaller 'at-risk' group, shows how PrEP citizenship is shaped by conflicting interests with roots in different understandings of PrEP and its potentials. While PrEP may be considered by the state as a means to contain HIV, it is understood by PrEP users as an opportunity to transform their sex lives and enjoy a new form of sexual freedom: sex without fear of HIV. Thus, as Epstein (2018) and Race (2016) have argued, sexual pleasure and wellbeing are key dimensions for promoting PrEP, yet are not reflected in the policies around it.

One of the implications of making PrEP more visible is that PrEP users contribute to producing social groups and imaginaries of PrEP users and non-users, which consequently influences how members of these groups see and experience themselves.

‘Working through’ PrEP: Processes of identification and acceptance

A process related to PrEP's increased use and visibility, emerging in the stories of this study's participants, is the social identity or feelings of kinship that PrEP invokes for some. Queer lives are marked by stigma and homophobia, entrenching feelings of shame that affect them every day to various extents. Bo explains how he understands this kinship to other PrEP users and how this relates to his own self-acceptance.

And taking PrEP, it kind of made me know that yes, you are a minority and yes, you are very much on your own. But... you're not alone. Well there's... there's a definitional issue that's different. Because no one is making a drug just for you. You know. There's a... a larger target group that needs it. Um, so this thing about meeting the community... Whether that community is just talking to people online or...
Bo describes how inclusion into PrEP citizenship offers kinship and feelings of collectiveness. As his sexual practices are now biomedically visible and accepted, and because he is aware that many other people use PrEP, he is now part of a larger community of PrEP users. Another participant, Stefan, who explained how he had been shamed for his sexual behaviour by healthcare professionals when he was younger, described how PrEP had facilitated greater self-acceptance in him about his sexual practices:

Well, I think it's been a contributing factor to the fact that, uh, I can say with pride that I like standing on Amager Fælled\(^3\) and getting it in the ass, and there are seven other people watching. It's a proud thing rather than thinking that this is something I'm ashamed of. (Stefan, 35 years old.)

The accounts of Bo and Stefan suggest that PrEP citizenship offers a legitimisation of their sexuality. The enrolment into the biosocial group of PrEP users may be experienced, as in Stefan’s case, as enrolment into a subversive or rebellious identity. Some participants emphasised other aspects of PrEP when talking about the identification processes related to it. Some explained how they related PrEP to other self-care practices such as yoga or taking vitamins. It is evident that active PrEP citizenship involves processes of self-reflection and identification.

For persons who do not want to ‘work through’ such processes of social identification, PrEP citizenship may be more difficult. Albert reflected on how the obligation to disclose and articulate sexual practices would have prevented him from seeking PrEP when he was younger.

Because now I've been out of the closet for so many years and... and I'm secure in my sexuality, but I also think that if you had asked me five years ago, I probably wouldn't have wanted to go to mine. To my own doctor to talk about PrEP. Because back then I was more insecure. Both about sexuality and about myself. (Albert, 21 years old.)

As such, while healthcare providers might aim for PrEP not to be exclusive to people who identify as gay, bisexual or trans, the imaginaries and activist therapeutic relationships enabled by PrEP constitute it as inherently queer. This tension in the exclusivity of PrEP points back to the requirements mentioned earlier to proactively self-educate and tactically perform vulnerability in order to obtain PrEP, for which certain resources, which are primarily found within the collectives of LGBTQ+ communities, are useful, or even necessary. Here, we once again see the complexity of PrEP citizenship, of which institutional requirements, cultural claims and social relationships intertwine to produce inclusions, exclusions, and pathways of care.

Discussion and concluding remarks

In this paper, we have examined how PrEP citizenships are produced and enacted by PrEP users in Denmark through different types of ‘work’. We have shown how this ‘work’ necessitates specific resources, such as the competence to ‘work out’ how the PrEP system is organised, identify ‘what works’ and proactively ‘work the system’ to one’s own benefit. The processes towards obtaining a prescription for PrEP entail self-education, as well as the education of GPs, which means that PrEP users carry out advocacy work for PrEP as soon as they start seeking it in the healthcare system. Furthermore, a continuous ‘working with’ the healthcare system, participating in regular control visits at the hospital, is essential for remaining on PrEP. We have illustrated how ‘working for’ PrEP as activist spokespersons is experienced as a moral obligation, yet raises a dilemma related to when to disclose one’s own PrEP use and the implications
of that. All these different types of work require a level of self-acceptance, or ‘working through’ of sexual identities and imaginaries of PrEP, potentially creating barriers to PrEP for people who fall outside of such identifications.

The different types of ‘work’ for PrEP citizenship that we have identified point to divergences between formal PrEP policy and how PrEP is actually used and experienced in the daily lives of users. For instance, we have noted a divergence in understandings of the aims of PrEP. PrEP may be used to foresee and plan prospective sexual pleasure and experimentation, which does not align with the formal scripts in which PrEP is only supposed to be prescribed to individuals who have been ‘at-risk’ involuntarily in previous situations. This discrepancy adds yet another layer to the obligations of PrEP citizenship, in that users have to adhere to formal medical criteria, i.e. be ‘at-risk’; while also adhering to moralities and rules of what Orne and Gall call the “sexual community infrastructures” (2019, 644), i.e. acquiring PrEP to prospectively gain sexual desirability as a partner for condomless sex. This discrepancy points to a broader tension between how PrEP, within a biomedical context, tends to be viewed as an individual medication reliant on individual criteria and adherence, versus how participants experience it as entrenched in their social lives. The biomedical model’s conformity to the “ideology of individualism” (Fee and Krieger 1993, 1481) has been commonly critiqued in the analysis of HIV/AIDS, in which the role of socioeconomic structures, discrimination and homophobia have too often been overlooked (Treichler 1987; Epstein 1996). In the context of PrEP, an increasing body of social science scholarship has argued for analytical frameworks encompassing the social complexities of PrEP use, rather than focusing on individual adherence (Auerbach and Hoppe 2015; Hughes et al. 2018; Kippax 2012; Race 2014; Skovdal 2019). As Fee and Krieger argue, from a purely biomedical standpoint, ‘at-risk’ groups

...consist merely of summed individuals who exist without culture or history. There is no acknowledgment of the fact that when ‘risk groups’ succeed in identifying populations at risk of disease, it is because these risk groups typically overlap with real social groups possessing historically conditioned identities (1993, 1481).

This argument for the significance of historical communities for the promotion of PrEP is echoed in our findings, which show how PrEP is promoted within queer communities on terms other than biomedical criteria. Although the medical definition of being enough ‘at-risk’ for PrEP is indeed viewed as an individual criterion, the activist and collective community efforts in being enrolled in PrEP seem to be carried out in alignment with community history and solidarity, meaning that the community definition of an eligible PrEP user is broader than the biomedical one. Activities which users engage in to ‘work for’ PrEP such as spreading information to other potential users about how to gain access to PrEP align with a collective interest in liberating PrEP to as many community members as possible, regardless of the individual’s momentary ability to live up to rigid criteria. Scholars have highlighted this tension between the queer community’s activist efforts to make PrEP widely available and free, versus healthcare systems’ focus on cost effectiveness (Brisson and Nguyen 2017; Orne and Gall 2019; Epstein 1996).

The number of people on PrEP in Denmark far exceeds the number expected and planned for by the Danish health authorities, highlighting PrEP’s successful spread and normalisation within queer communities. Once again, their sense of responsibility and care for each other renders them able and willing to live up to the ‘work’ of PrEP citizenship. However, as we have shown in this study, it is likely that the gatekeeping measures surrounding PrEP access, including the demands of navigating the healthcare system, articulating sexual practices in the ‘correct’ way and partaking in institutional surveillance, as well as self-monitoring, require resources that may not be available to those who might benefit the most from it. Our findings suggest the salience of social class structures for participation in PrEP citizenships, in terms of both
material barriers (such as working hours, means of transport, health literacy) and symbolic barriers (such as not identifying as LGBT+), echoing Roberts and Tutton’s argument for including the embodiment of social class into analyses of biocitizenship (2018). All in all, the complexity and paradoxical nature of PrEP accessibility calls for further investigation, addressing PrEP citizenship as a socially embedded collection of ‘workings’ that make available particular privileged social rights and experiences of queer kinship, yet are not desirable or possible for all potential users to engage in.

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Notes

1 Original citation in Danish: "...farmakologisk supplement til den eksisterende forebyggelsesindsats, der fortsat skal have fokus på sikker sex, tidlig opsporing og effektiv behandling."

2 Checkpoints are community clinics run by the Danish AIDS foundation which offer testing and other services, especially related to LGBT+ health.

3 Amager Fælled is a large park area in Copenhagen which is used for cruising.