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# The People vs the NHS: Biosexual citizenship and hope in stories of PrEP activism

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## Abstract

Discourses of pre-exposure prophylaxis (PrEP) revel in its radical potential as a global HIV prevention technology, offering a promise of change for the broader landscape of HIV prevention. In 2018, the British Broadcasting Corporation (BBC) aired *The People vs The* NHS: Who Gets the Drugs?, a documentary focused on the 'battle' to make PrEP available in England. In this article we explore how the BBC documentary positions PrEP, PrEP biosexual citizen-activists, as well as the wider role of the NHS in HIV prevention and the wellbeing of communities affected by HIV in the UK. We consider how biosexual citizenship (Epstein 2018) is configured through future imaginaries of hope, and the spectral histories of AIDS activism. We describe how The People crafts a story of PrEP activism in the context of an imagined gay community whose past, present, and hopeful future is entangled within the complexities and contractions of a state-funded health system. Here, PrEP functions as a 'happiness pointer' (Ahmed 2011), to orient imagined gay communities towards a hopeful future by demanding and accessing essential medicines and ensuring the absence of needless HIV transmissions. This biomedical success emerges from a shared traumatic past and firmly establishes the salvatory trajectory of PrEP and an imagined gay community who have continued to be affected by HIV. However, campaigns about the individual's right to access PrEP construct the availability and consumption of PrEP as an end goal to their activism, where access to PrEP is understood as an individual's right as a pharmaceutical consumer.

## Introduction<sup>ii</sup>

'Turns out there <u>is</u> a magic pill that stops you getting HIV[human immunodeficiency virus]', HIV Scotland proclaims in a 2019 poster campaign depicting a sparkling medicine bottle. Despite its complexity, discourses of pre-exposure prophylaxis (PrEP) largely revel in its radical potential as a global HIV prevention technology, offering excitement around a promise of change for the broader landscape of HIV prevention. Thus, PrEP is not simply a new biotechnology, it also acts as a generator of hope for the future. Its implementation, however, has in large part been reliant upon 'citizen' action through activist movements, and

poses significant challenges to health systems as it blurs the lines between prevention and treatment, disrupting existing organisation of services and HIV prevention practices, both within and beyond the clinic. Health provision more generally is undergoing radical change with expanding incorporation of new biotechnologies and increasing expectations of self-management (Shim 2010). However, whilst United Kingdom health budgets stretch to accommodate competing demands and growing health complexities, austerity has reduced public funding, moving health systems further away from their welfare state origins in the post-war period. PrEP and its complexities enter into the UK health landscape at a moment when state-funded health provision is becoming increasingly reliant on patient-citizens and their capacity to navigate biotechnologically advanced, but underfunded, systems (Keogh and Dodds 2015).

In 2018, the UK's National Health Service (NHS) reached its 70<sup>th</sup> anniversary. In commemoration, the British Broadcasting Corporation (BBC) television and radio service ran two weeks of programmes reflecting on its history and contemplating its future. *The People vs The NHS: Who Gets the Drugs?* focused on the 'battle' to make PrEP available in England, charting the role of community activism in changing NHS England's HIV prevention policy. An HIV documentary is not out of place in this series, or in the wider visual culture and histories of HIV. Indeed, we have seen a proliferation of films and other visual materials around HIV and AIDS activist histories emerge in parallel with PrEP (and other HIV) developments (e.g. Hubbard 2012, France 2012, weRAGEon 2018). As such, this documentary, informed by and contributing to this visual field, allows us to consider how these cultural narratives contribute to and shape what we describe as wider PrEP imaginaries. We suggest PrEP imaginaries – and in particular how PrEP activism is positioned and/or curated as a cultural object of community storytelling within this well-established visual history of AIDS activism – are, at present, little explored within current social science and

humanities PrEP scholarship. Thus, with activism scholarship focusing largely on early responses to AIDS (e.g. France 2012, Diedrich 2016) and social science literature examining the lived experience of communities accessing PrEP (e.g. Witzel, Nutland and Bourne 2019, Martinez-Lacabe 2019), we turn to the emergence of contemporary HIV activism through PrEP to consider how it is culturally, socially, and historically shaped. Moreover, due to the demands on patient-citizens, we argue that there is a need to be attentive to how enactments of particular forms of biosexual citizenship (Epstein 2018) emerge within and in response to these wider PrEP imaginaries, in the context of – or even constitutive of – PrEP activism. How does biosexual citizenship and PrEP activism sit within and speak to the wider history of HIV, and how is this portrayed? What role is played by the changing somatechnic assemblages of HIV in the development of PrEP imaginaries, particularly the complex and undefined relationship between embodiment, technology, and bodily practice (Pugliese and Strkyer 2009)? In this article we focus on how the BBC documentary positions PrEP, PrEP biosexual citizen-activists, as well as the wider role of the NHS in HIV prevention and the wellbeing of communities affected by HIV in the UK.

## Background

PrEP is a prevention strategy for people who are HIV-negative. This is the use of existing (tenofovir-based) HIV antiretrovirals which can either be taken daily or 'on-demand'. Despite 2012 US Food and Drug Administration (FDA) approval, regulation, implementation, and availability of PrEP varies widely and continues to be debated. Globally, PrEP is available in a growing number of countries (France, Kenya, South Africa, Australia, Canada, Ireland) through either demonstration trials, pilot projects or part of the health system (Beyrer et al. 2016). PrEP provision and access within the UK – a country of multiple health systems – is equally fractured. At the time of writing, the National Health Service (NHS) England has not

yet commissioned PrEP through its sexual health services.<sup>iii</sup> In contrast, PrEP has been available in Scotland, free-of-charge, through NHS sexual health services since July 2017; PrEP became available in Wales through the three-year PrEPARED trial in July 2017 with no maximum capacity; and a two-year pilot started to offer PrEP in September 2018 in Northern Ireland.

In response to the slow and uneven roll-out of this new HIV prevention option, PrEP activism in the UK (largely England) has been led *most visibly* by gay and bisexual men and HIV clinicians (Caughill 2017, Portman 2016). This activism has heightened in response to NHS England's policy indecision and delayed provision, as well as the considerable disjuncture between the demand for PrEP and the opportunity to obtain PrEP through conventional medical sources (Paparini et al. 2018). Community activists have also created online 'DIY' support mechanisms to navigate access to generic PrEP for personal use, often compared to the AIDS (Acquired Immune Deficiency Syndrome) buyers' clubs in the early years of the epidemic (e.g. Caughill 2017) where activists in the USA made medication available which had not yet been approved by the FDA (France 2016).

Grassroots activism has also played a key role in challenging NHS England's refusal to commission PrEP. Campaigners mobilised alongside the National AIDS Trust's 2016 judicial challenge, lobbying for NHS availability in England and disputing the claim that preventative healthcare sits within the domain of local authorities (BBC News 2016). Despite the high court judgment that HIV prevention – and PrEP – were within the purview of NHS England, full provision has not yet materialised. Instead, NHS England commissioned the three-year IMPACT trial, with an initial capacity of 10,000 participants. In June 2018, the capacity of the IMPACT trial was expanded to 13,000, and the 2,000 places reserved for people from groups other than gay and bisexual men was reduced to 1,000 in order to free more trial places for men who have sex with men (MSM), who were reportedly being turned

away due to a lack of spaces (National AIDS Trust [NAT] 2018). Grassroot campaigns continued to advocate for full provision through NHS England services.

Whilst PrEP has been celebrated as an essential tool in HIV prevention, it does not provide a solution to all HIV transmission and 'risk', and structural barriers to healthcare and information, and socio-cultural and economic inequalities still persist (Witzel, Nutland and Bourne 2019). All routes to PrEP access in the UK, including clinical trial, NHS provision, private prescription, pilot clinic, and online DIY self-sourcing, either strongly encourage or require continuous medical contact and surveillance. US guidelines and PrEP practices demand a similar compliance to supervision and a high degree of regulation (Holt 2015, Orne and Gall 2019). Martin Holt suggests that the 'greater sexual freedom' offered by PrEP may come at a price, both financially and in terms of 'medical scrutiny' (2015: 436). Surveillance brings different consequences and potential penalties for different subjects. Feelings of discomfort about close medical surveillance may make some wary of participating (or unable to participate) in current PrEP trials, especially if previous clinical encounters have been detrimental or injurious in some way. Undocumented migrants may be asked to prove their identity, fear the sharing of their data with the Home Office, or may struggle to register with a local medical practice in the first place. As Nikolas Rose (2007: 132) observes, 'not all have equal citizenship in this new biological age'.

In the context of contested access to and increasing activism around PrEP, the experiences of people who use, or would like to use, PrEP have been and continue to be widely shared. Activist blogs like PrEPster's *My PrEP Story* (2020) appear alongside a growing body of research (Martinez-Lacabe 2019, Paparini et al. 2018, Witzel, Nutland and Bourne 2019). What these sources have in common is both an engagement with changing meanings of HIV, as well as assertions of rights and responsibilities as sexual citizens (Richardson, 2017). For instance, some PrEP users have described 'no longer living under the

threat of HIV' (Koester et al. 2017, Martinez-Lacabe 2019). In contrast, the responsibility and duty to manage risks through the use of PrEP, and the uneven biomedical governance produced through this new technology have also meant that its liberatory potential is uncertain (Young, Flowers and McDaid 2016, Orne and Gall 2019).

Activism, citizenship and hope

In the early UK AIDS epidemic, gay, and bisexual men played a central role in leading political responses and promoting collective action (Keogh 2008). These initial responses of biomedical activism – or enactments of biological citizenship, according to Rose (2007) – have had a lasting impact (France 2016, Young 2016). Ingrid Young et al. (2019:3) chart the trajectory of biological citizenship and HIV, describing how citizenship is 'governed through both rights and responsibilities: the rights to biotechnologies, treatment and care and the responsibility for the health and well-being of oneself and others'. Grounded in this activist HIV history, we suggest that biological citizenship is not only a concept which applies to those living with a long-term health condition, but also applies to those engaged in or affected by collective entanglements with biotechnologies. These communities are important places for somatechnic consideration (Pugliese and Stryker 2009). Certainly, within the context of the PrEP activism we describe above, self-governing sexual actors – and their clinical allies – demanding access to pharmaceutical prevention to reduce risk of HIV serves to highlight the ways that contemporary enactments of biological citizenship are entwined with not only biotechnologies and shifting notions of illness, but the sanction of these biotechnologies by, as well as the organisation of, state-funded health systems. Consideration of biological citizenship therefore requires that we pay attention to the social location of biological citizens and how rights and responsibilities might be affected by social inequalities and fractured communities within a neoliberal health system which emphasises individual health practices,

health 'choices', and a shrinking of state obligation to provide care for its citizens (Mol 2006, Richardson 2017). Moreover, the social location of biological citizenship in PrEP and HIV prevention practices needs to consider the role of sexuality.

Through the construction of the collective queer memory and the historical trauma of AIDS, sexuality has and continues to play a fundamental role in contemporary discourses of risk, prevention, health, and wellbeing. Sexual citizenship, or as Richardson (2000) describes, the access to a system of sexual rights, comprising a complex entanglement of conduct, identity and relationship-based claims, shapes ways of engaging with PrEP and related healthcare activism. Sexual citizenship involves negotiating normative assumptions of sexuality and sexual practice, as well as obligations necessitated through particular modes of sexual citizenship which hold the potential to impose moral judgement or behavioural/conduct-based restrictions (Richardson 2017). Relatedly, Peter Keogh (2008: 599) argues that the construction of gay men in health promotion since the early 1990s has moved from 'intrinsically risky individuals' towards subjects who have 'a capacity to manage risk'. Thus, citizens' own actions, or inactions, are understood as fundamental to their own (and others') capacity for 'risk' or 'vulnerability' to disease. This produces a personal responsibility – or obligation of sexual citizenship – and an 'ongoing activity of selfactualisation' (599) which places expectations upon – in this case – gay men to not only perform specific healthy and medicalised practices (Squire 2009), but also to demonstrate particular identities; a duty to 'become the right type of person' (Keogh 2008: 600). Gay men are therefore required to be good sexual citizens as they navigate HIV prevention and management.

PrEP activism invokes concepts of both biological and sexual citizenship. We are particularly interested in how specific sexual identities, communities, and practices are entangled with the biosocial of HIV prevention, producing a form of *biosexual citizenship*.

Steven Epstein recently examined these links in his exploration of sexual health institutions in the early twentieth century. He defines biosexual citizenship as:

differentiated modes of incorporation of individuals or groups fully or partially into a polity through the articulation of notions of rights and responsibilities, in cases where biological and health-related processes are brought into some relation with sexual meanings or identities ... [this] intersection ... calls attention to how embodied pleasures and risks associated with sexuality figure in the worlds of biomedicine and public health, as well as how public health officials, in engagement with others, participate in defining sexual rights and responsibilities. (2018: 26)

We agree with Epstein that biosexual citizenship is about the interplay between, across, and at times in tension with the sexual (sexual meanings, practices, and/or identities) and biological (biomedicine and public health). To apply this to PrEP activism, then, it is important to consider if and how somatechnic assemblages of HIV are formed through PrEP activists' interactions with health systems (Pugliese and Stryker 2009), but also to consider who these activists are and how these collectives are socially situated.

Moreover, given the long history of HIV activism, it is not enough to only explore the social location of biosexual citizenship, but also to consider its *temporal* orientation. While contemporary engagement with HIV biotechnologies, such as PrEP, speak of a future of eradication, they are also firmly grounded in an AIDS past, belying a particular affective and temporal orientation. We draw on Sara Ahmed's (2011) analysis of hope to illustrate how the BBC documentary constructs PrEP access as conducive to happiness. Ahmed contends that objects can orient us towards emotions or can be imbued with emotions themselves. We explore how PrEP, a biotechnology understood to be transforming the HIV prevention arena,

is positioned as a 'happiness pointer' (Ahmed 2011), orienting its users and advocates — 'responsible' biosexual citizens — towards hopeful, happy, and healthy futures. Following Ahmed, we are interested in the temporality of feeling, 'how [objects] keep the past alive, and how they involve forms of expectancy or anticipation of what follows' (2011: 172). As a biotechnology with prophylactic, temporal and affective promise, PrEP functions as a somatechnic tool, blurring distinctions between the embodied and the technologised (Pugliese and Stryker 2009). We are interested in how biosexual citizenship is configured through these future imaginaries of hope, a sense of what kind of lives count as a 'good life' (164), and the spectral histories of AIDS activism.

## Materials and Methods

Our project, 'Sex, drugs and activism: negotiating biological citizenship and pharmaceutical prevention', uses HIV Pre-exposure prophylaxis (PrEP) in the UK as a case study to explore the entanglements between sexuality, activism, and biological citizenship in relation to the use of pharmaceuticals for HIV prevention. The project sought to engage with questions around how activism relating to the implementation of pharmaceutical prevention technologies shapes and transforms the relationship between communities and public and private health provision.

The project comprised a range of different creative, ethnographic, and digital research methods, and included analysis of documentaries, memoirs, and cultural texts. The focus of this article is our analysis of one such documentary, *The People vs The NHS: Who Gets the Drugs?* (hereafter *The People*). *The People*, a BBC Two television documentary programme, first aired at 9pm on the 27 June 2018. The hour-long documentary, made by Pulse Films in partnership with the Open University, provides insight into the legal battles concerning the

provision of PrEP on the NHS and the inception of websites to support people based in the UK to source reliable suppliers of generic PrEP.

Here we draw on our analyses of *The People* to explore how biosexual citizenship emerges in and through PrEP activism, and how this activism sits in the wider history of HIV and health activism. The first stage of our analysis was to collectively watch *The People*, responding, noting, and reflecting on issues which we individually and mutually identified as key thematic and narrative strands. Our analysis has developed from multiple 'watchings' and ongoing discussions, and these repeated engagements with *The People* enabled the development of thick descriptions and the identification of narratives that we then sought to organise into meaningful patterns and themes.

Through our analysis we considered how the politics of PrEP are constructed in popular media and, thus, presented to wider publics. We examine the role of visual narrative representation – as a somatechnic process (Moffat 2018, Stryker and Sullivan 2009) – in shaping PrEP imaginaries. We use 'PrEP imaginaries' as a means of engaging not only with the lived experience of a new HIV biotechnology, but the hopes and anxieties that accompany the necessary reconfiguration of HIV prevention, sexual practice and biosocial identities, as well as the cultural representations and constructions through which 'we make sense of' and give coherence to these experiences and feelings (Gatens 1996: viii, Pugliese and Stryker 2009). In particular, we are concerned with how and if biosexual citizenship is enacted, bounded and/or reconfigured through PrEP activism and investments in imagined PrEP futures. We are therefore attuned to biocultural and somatechnic assemblages of HIV, including medical and 'non-medical issues' such as gender, embodiment, pleasure, memory, and 'community', as well as the entanglement and reciprocal constitution of these practices and ways of being (Stacey 2010: 8, McCormack 2016: 137, Pugliese and Stryker 2009).

The BBC's *The People* starts with depictions of loss: a candle-lit vigil attended by mourners; prayers, lowered heads, crying; a list of names of those being grieved. HIV is immediately grounded in the early AIDS epidemic of the 1980s. London activist, Marc Thompson, explains the continuing influence of the 'historic' AIDS crisis: 'the early days of the epidemic ... was about death: a long, painful death that hit really young people, young men, in the prime of their life'. Although historical depictions of HIV (such as France's 2012 American documentary film, How to Survive a Plague) characterise antiretroviral therapies (ARVs) as providing a revolutionary change in the landscape of HIV, anxieties about AIDS are shown to persist. Thompson adds, 'that spectre of death and illness just hangs. I mean, it's hung over the gay community particularly, for over – nearly thirty-five years now'. This point is reiterated when Greg Owen, co-founder of iwantprepnow (IWPN), recalls the moment he received his HIV diagnosis. He notes that he immediately envisioned images of death from the early epidemic, feeling that 'the heritage of my community suddenly became mine'. Owen is shown walking through a shop-lined street, his surroundings sun-bleached and slipping in and out of focus whilst the voice of a newsreader reports the death of Freddie Mercury accompanied by a slow tempo piano melody which recurs throughout the documentary. The lasting impact of the AIDS crisis of the 1980s and 1990s upon contemporary gay culture specifically has also been widely documented (Dean 2011, France 2012, 2016) and realised in multiple filmic depictions of HIV and AIDS. Jih-Fei Cheng (2016: 83) notes that 'AIDS media production and audience reception perform a collective practice of care. We hold dear the deaths of others – as we experience our own viscerally imagined vulnerability to death'. The People draws on well-established tropes of AIDS history and loss for a specific community of gay and bisexual men to frame its narrative of HIV generally, and PrEP specifically.

Following the opening sequence of death and grief, a red-tinted intertitle overlaid onto black and white photographs of hospitalised bodies, reads: 'More than 30 million have died from HIV and AIDS around the world. Today, advances in medical science mean that HIV no longer has to be a death sentence'. By opening with historic scenes of mourning and illness, *The People*, like other AIDS documentaries (France 2012) carves a narrative trajectory of hope and success, in which biomedical developments offer transformative benefits even to those who are considered 'at risk' of transmission, whilst also re-shaping our understanding of HIV. Illustrating this development in the next scene, Gus Cairns, editor of the online HIV information resource National AIDS Map (NAM) is shown holding up his weekly pill organiser which rattles with daily ARV drugs. The People foregrounds this junction of HIV past and HIV present, in which the trope of illness and death has been transformed into one of treatment and survival. As Tim Dean (2011: 78) argues, 'the standard narrative of disease progression has been disrupted'. Due to effective ARVs, Dean (75) contends that the 'one thing we thought we knew for sure about infection with HIV – that it is invariably fatal – has become, in recent years, ever more uncertain'. Transforming modes of sexual citizenship are cultivated within these stories of biomedical and biosocial progress and set the groundwork for an emergent biosexual citizenship.

## Норе

Hailed as a 'miracle' drug and a transformative new prevention option, PrEP has produced a narrative of optimism that now transcends the initial reprieve found in HIV treatment (Race forthcoming), moving us towards a new generation of biomedical prevention. It is in this vein that *The People* presents PrEP as 'a drug that could end the most deadly epidemic of modern times', with Yusef Azad, from UK HIV policy charity National AIDS Trust (NAT), explaining that 'PrEP is the additional tool we need to really get on top of the epidemic'.

PrEP is rendered a biomedical breakthrough, a 'medical miracle', and the ultimate innovation for HIV, with particular significance for gay and bisexual men. Sexual Wellbeing Advocate, David Stuart, emphasises this: 'HIV's a huge thing in gay men's lives. And PrEP can change that'. HIV in *The People* is established as an issue for *all* gay men, not only those with a positive status. We see here how HIV prevention technologies are entangled with particular sexual politics, community identities, and expectations for biosexual citizens.

In the documentary, Greg Owen argues that PrEP can enable 'fear-free sex' for gay and bisexual men, echoing claims by PrEP advocates and users that PrEP is a source of hope and optimism (Koester et al. 2017). With its promise for positive personal change, PrEP becomes a 'happiness pointer', wherein objects proclaim that 'to follow their point would be to find happiness' in the future (Ahmed 2011: 163). Expectations about the future (including a move towards progress, change, and happiness) are fundamental to citizens' participation in their own healthcare as biological citizenship 'operates within the field of hope' (Rose 2007: 135). Rose (2007: 136) reflects on the role of affect, 'the fear of illness, [in generating] despair, desperation, and terror in the face of the future'. The ideology of hope, however, compels citizens to respond to these fears. As Rose (2007: 148) explains, 'it postulates a certain achievable and desirable future, which requires action in the present for its realisation'. Whilst some potential PrEP users may feel ambivalent about the self-governing practices required by PrEP (Young, Flowers and McDaid 2016), the documentary depicts PrEP as liberatory and therefore necessary: a 'happiness pointer' and a source of hope.

Framing PrEP in this way transforms how HIV transmission is positioned within *The People*. Greg Owen describes how, in an era of PrEP, '10-12,000 people *needlessly* contracted this highly stigmatising – what can be a life-ending – condition for some people' (our emphasis). Owen's understanding of HIV transmissions – including his own – that have occurred since the advent of PrEP as 'needless' illustrates the perceived primacy of PrEP as

an *essential medicine* for prevention (Greene 2011). Its transformative potential casts all HIV diagnoses as avoidable. Thus, nestled within the field of hope is a narrative of 'what could have been' for those living with HIV. Although this particular contemplation is not uncommon in narratives of people living with HIV (Squire 2009), hopeful narratives in the context of PrEP and within this documentary establish a very clear and biotechnologically determined orientation. Owen's position as a central figure in the documentary not only directs us to the significance of *IWPN* and the early grassroots purchase on PrEP provision, but as we go on to show, Owen also embodies the 'what if' narrative and thus, with his hindsight, he becomes a beacon of hope.

## Activisms

The optimistic outlook engendered by PrEP has given rise to a resurgence in grassroots HIV activism (Paparini et al. 2018). In the BBC documentary, Alex Craddock, co-founder of *IWPN* describes the formation of the website and how, despite his and co-founder, Greg Owen's inexperience, they felt an urgency to assist with providing greater access to PrEP in England. Craddock notes, 'I was new to this, but I was ready to jump in with both feet. And that's exactly what Greg was doing too'. The development of the website, shown in the programme alongside street protests for improved access to PrEP, are framed as an outlet for the rage and frustration many gay and bisexual men were understood to be feeling. Sitting in the same loft bedroom he and Greg used to plan the launch of *IWPN*, decorated with the iconic 'SILENCE = DEATH' poster, Craddock adds that, 'the whole point of the website was that it was radical and direct, 'cause we were angry'. For PrEP activists in *The People*, an optimistic outlook is interlaced with a responsibility and expectation to 'act'. Sexual Wellbeing Advocate David Stuart reflects on the emergence of PrEP: 'at the time we were diagnosing five people a day with HIV. That's a lot of people. And each one of them – don't

think of them as a number – think of each one of those individuals'. Once more, the film demands the 'what if' question whilst underlining the avoidability of transmission in an era of PrEP. For those sharing their stories in the documentary, the needless acquisition of HIV is repeatedly framed as a prompt to act collectively to create greater awareness of, access to, and use of PrEP. Here, we see how an 'affective community' (Ahmed 2011: 166) is arranged around PrEP. In its promotion as a social good, the community 'are aligned; we are facing the right way', consuming PrEP as a way of orienting themselves towards a better future.

Kane Race (2009: 118), exploring the role of community memories in contemporary HIV prevention, describes 'a certain sentimental hankering ... for the days of the crisis, when politics were authentic and community pure'. Early AIDS activism not only sets a precedent for contemporary strategies, it also offers a benchmark for the (in)validation of the work undertaken. In *The People*, PrEPster co-founder Will Nutland explains that, in collaboration with clinician Mags Portman, he presented his own body to be used as a test to confirm the authenticity of PrEP purchased online when this first became viable. He is shown opening a box containing multiple pharmaceutical packages before holding a glass of water in front of a bathroom mirror, placing a bright blue pill on his tongue – mouth open in the reflection – then swallowing. This narrative invites memories of activist and clinician alliances of the late 1980s and 1990s where, for example, ACT UP (AIDS Coalition to Unleash Power) in the United States campaigned for 'drugs into bodies' and for AIDS activists and people living with HIV to be given greater influence over, and involvement in, drug trials. Nutland's account also establishes the body itself as a site of activism, exemplary of biological citizenship in general, and of biosexual citizenship in particular. In this instance, the biological/consumer citizen enlists to ingest and test these drugs in order to assure others (perhaps particularly those in his affective community) of their safety. Embedding this somatechnic process within the health system, however, also invokes a specific kind of

legitimacy, requiring 'informational biocitizenship' (Rose 2007: 135) – medical and pharmaceutical knowledges – whilst also situating the activism within a public/private nexus. These drugs are accessed independently of the NHS, but nevertheless tested in alliance with NHS workers, an example of the entanglements of activism and biosexual citizenship within a wider health system.

#### Heroes

Greg Owen, the central activist figure in *The People*, is depicted as a beacon of hope in the story of the availability and transformative potential of HIV preventative biotechnologies. The film follows Owen as he shares his personal experiences of growing up 'very gay' in the 1980s in Belfast, Northern Ireland, during 'the Troubles'. Low resolution video footage shows Owen as a child, pink-cheeked and smiling in a striped sweatshirt as he turns to face his audience, looking into the video camera behind him. In another clip, a young Owen in grey trousers and a lemon shirt is seen Irish dancing in a hall. A series of still images illustrate Owen's childhood: we are shown Owen in a row of children in matching outfits posing against a brick wall, followed by a succession of photographs of Owen's adolescence accompanied by an audio track of 'It's a Sin' by the Pet Shop Boys.

Owen tells the story of his transition from Belfast to London aged 25, where he describes his life changing drastically: 'within six weeks I went from this geek kid to being an A-gay' with a 'hard and fast and [passionate]' approach to life. Whilst the mobilisation around PrEP provision and access in England is shown to have been a collective endeavour, involving charities, multiple individual actors, and campaign groups, Owen's biographical ruminations place him at the forefront of the story, illustrating the individualising potential of biological – and by extension biosexual – citizenship (Rose 2007: 134). In *The People*, Owen is presented as the principal actor of social change. Keogh (2008: 601) proposes that there

may be a relationship between the 'the great gay mythic narrative (the "coming out" story)' which demands a 'neutral perfectible gay identity' and the propensity for individualistic health promotion for gay men. He notes that '[t]he development of gay identity is often described as a process of self-interrogation, self-analysis and self-development' (601). In assembling a picture of Owen's background and his suitability for PrEP, the documentary presents his journey as one of learning, reflection and betterment, and foregrounds the specific orientation of biosexual citizenship.

Furthering Owen's personal narrative, *The People* also introduces his mother, Christine McGeown, who describes Owen's HIV positive status as initially 'absolutely devastating'. However, as she is pictured sitting at a kitchen table, she recalls that over time she realised, 'what's me crying going to do? He's to live with it, it's his actions, his consequences. No one's perfect and no matter what your child brings to your door, you're always going to support your child'. Whilst McGeown's response could be understood as both compassionate and benign, her reflections – which also emphasise her son's responsibility – gesture towards the broader neoliberal message behind the film: HIV transmission is governed by the behaviour of the individual, who holds the power to 'actively [shape] his or her life course through acts of choice' (Rose 2007: 134).

This core strand runs throughout the film but is especially apparent in Owen's elaboration of his personal mission, which arose after receiving his HIV diagnosis. In his final lines in *The People*, Owen describes:

I had a humble objective, like a really basic objective. I just want one person to remain HIV negative on the back of my diagnosis, that way it's HIV equal. And if we prevent one – a second person, then I won. My HIV status didn't cost anything.

Seroconversion bestowed upon Owen a sense of purpose: the necessity to act and to offer others the opportunity with PrEP that he missed. Professor Sheena McCormack, Chief Investigator on the PROUD trial, explains how Owen 'can take credit for [the reduction in HIV diagnoses in England]'. Owen adds that McCormack encouraged him to 'strip it back, think about the people. Like there are thousands of people walking around now, HIV negative, because of something that *you* did'. This is presented as an individual victory for Owen, as well as a common good. Owen's personal commitment to become 'HIV equal' in order to counteract the public costs incurred as a result of his diagnosis also engages with – and implicitly endorses – attributions of responsibility and culpability, despite his own attempts to remedy the expense. In taking on this mission, the perceived 'recklessness' of his HIV acquisition is replaced by 'good' biosexual citizenship, 'to decrease the burden on society and claims on the state' (Richardson 2017: 133). This sense of personal responsibility and self-management, as Richardson (133) observes, accords with the state's needs and interests.

Hence, whilst PrEP remains unavailable on the NHS in England, Owen also becomes accountable for others, 'passing around' PrEP as a happiness pointer (Ahmed 2011: 164), which then 'accumulat[es] positive affective value as [a social good]'. For example, Owen describes sharing a Facebook status about receiving his diagnosis of HIV to make others aware of his news. As he walks through a dark street, with strings of sparkling blue lights overhead, a Facebook interface overlaid onto the moving image shows Owen's status being typed in three stages:

I AM HIV+

So that was easier to type than I thought.

## Guess I won't be needing PrEP now. X

Owen recalls that sharing his HIV status on this platform was a "ding!" moment' where 'your whole life changes', as his 'phone just lit up' with responses from people who were HIV negative and hoping to discover more about PrEP. This attempt to share his HIV status through social media is now remembered by Owen as his initial entry into PrEP advocacy. Whilst he was no longer eligible to make use of this medication himself, as a member of an emerging – and hopeful – biosocial community in the age of PrEP (Young 2016), Owen may have found 'hope in passing something on, where the project or task is to keep passing' (Ahmed 2011: 175).

#### Villains

The People establishes an antagonism, repeatedly characterised as 'a David against Goliath battle', between NHS England and those at the centre of PrEP lobbying campaigns, particularly the National AIDS Trust, who instigated a judicial challenge by the High Court of Justice to challenge NHS England's decision not to provide funding for PrEP. This controversial decision had previously been defended by NHS management because they argued preventative healthcare sits within the domain of local authorities (BBC News 2016). Owen is one of many campaigners in the documentary to express his disappointment, reflecting that he 'felt worse about [NHS England's decision to refuse PrEP] than I did about my HIV diagnosis'. Alex Craddock, co-founder of *IWPN*, recalls how inaction from the NHS led to their intervention: 'If they're not gonna do it, fuck the NHS, we're gonna tell everyone how to get PrEP'.

Following their initial resolution against funding PrEP, *The People* reports that NHS England published a press release describing PrEP as a prevention tool 'particularly for men

who have high risk condomless sex with multiple male partners' (NHS England 2016). Ian Green, Chief Executive Officer (CEO) of British HIV and sexual health charity Terrence Higgins Trust, reflects on their depiction of PrEP users as 'condemnatory', with Owen adding that it 'felt really vicious actually, it felt like sour grapes'. Yusef Azad, NAT, refers to the release as 'homophobic', showing 'an institution just lashing out'.

The juxtaposition of HIV with gay male sexualities in the NHS press release, with particular emphasis on the number of sexual partners and the 'risk' of their practices, is recognised in the documentary as a familiar, albeit outmoded, narrative, echoing concerns about 'reckless' and 'complacent' behaviours as a result of ART 'treatment optimism' in the 1990s (Race forthcoming). Will Nutland describes how media responses to the press release evoked the early years of the AIDS crisis, where discriminatory attitudes contributed to HIV stigmatisation and forged barriers to treatment, in this case questioning the need for the rollout of PrEP whilst vilifying gay, bisexual, and other men who have sex with men (MSM). Nutland notes that it felt like 'history repeating itself', as though they were 'taking a step backwards', and Owen recalls seeing 'headlines we hadn't seen the likes of since back in the days of AIDS'. A series of print media news reports fill the screen, including one asking, 'Why should WE pay for gays to have unsafe sex?' and another which simply states, "PROMISCUITY PILL". A number of the documentary's contributors discuss how homophobia may have played a role in the public imaginaries of PrEP. Nutland notes, for example, that journalistic accounts were 'peddling this idea that our health and our rights are somehow less than other people's rights', whilst Owen argues that PrEP provision has not been granted due to the perception that 'some lives don't matter as much as others'. Both the NHS and the wider media are cast in opposition to the rights of communities of gay men to access essential health care, thus highlighting the complexities of negotiating biosexual citizenship within a heteronormative environment.

The documentary also points to another explanation for the lack of PrEP provision. Adam Hundt, a solicitor representing NAT, explains that 'there's actually a bigger issue here – it's not actually about PrEP. This was about the NHS trying to cut without cutting'. These financial predicaments are only briefly situated in the well-documented debates around the impact of privatisation and austerity on the NHS in the UK, instead emphasising the ideological priorities that influence NHS spending. For example, Hundt reflects on how the NHS began 'pitting one patient group against another patient group' by 'offset[ting] PrEP against cancer treatment for children – emotive stuff like that'. This is corroborated by a BBC News clip of Jonathan Fielden, NHS England, who is shown standing in front of a hospital entrance, explaining that PrEP would 'be seen and considered alongside thirteen other treatments, including treatments for children with cystic fibrosis, prosthetic limb loss and certain types of auditory implants'. Through Hundt's framing, we can read an implicit accusation from the NHS that gay/bisexual men (especially those whose behaviour is described in the NHS press release) are potentially less deserving, less responsible biological citizens, as both Nutland and Owen suggested above. Campaigners thus position the self-care and self-regulation practiced by PrEP users, 'good' [bio]sexual citizens (Richardson 2017: 133), in opposition to the stance of the NHS. Their entitlement to NHS provision is constructed as fundamental to their ability to live a 'good life'. As Ahmed (2011: 164) describes, a life 'must take on the direction promised as a social good' in order to count, and in *The People*, PrEP is shown to point towards a futurity of happiness, longevity, and health.

Whilst the successful court battles provide community achievement as closure for the documentary, NHS England has still not granted full provision at the time of writing, and the unavailability of PrEP is positioned as a critical disruption to a post-AIDS futurity, a trajectory pointing towards an optimistic, happy conclusion. *The People* therefore depicts

specific, acute frustrations directed at the health services by campaigners, and PrEP activism, and its specific aims as portrayed in the documentary, thus offers the possibility (or desire) to circumvent health systems. Craddock, for example, remembers deciding, 'we don't even need the government right now, we can do it ourselves'. Their approaches, however, are shown to be fundamentally entangled within medical networks, with Nutland testing PrEP with support from an NHS clinician, and Owen asking for guidance from a friend working in the NHS, who provided anonymised data on the efficacy and legitimacy of generic PrEP before they launched the website. The titular role of the NHS as the programme's antagonist is continuously obstructed by these support mechanisms, as well as the personal relationships shown between clinicians and activists. While enactments of biosexual citizenship within PrEP imaginaries may rely on clearly established villains, biosexual citizenship is at the same time entangled in a complex relationship with these very villains as part of a wider neoliberal health system (Mol 2006).

#### Conclusion

The People crafts a story of PrEP activism within an imagined gay community (Anderson 2006 [1983], Young 2016, Formby 2017) whose past, present, and hopeful future is entangled within the complexities and contractions of a state-funded health system. This narrative illustrates how particular enactments of biosexual citizenship are constitutive of PrEP activism and play a critical role in PrEP imaginaries. The People frames HIV temporally: the construction of a PrEP story in The People invokes spectral histories of AIDS to place PrEP in a particular history of gay men; while at the same time PrEP functions as a happiness pointer, to orient imagined gay communities towards a hopeful future by demanding and accessing essential medicines and thereby (ultimately) ensuring the absence of needless HIV transmissions. This biomedical success emerges from a shared traumatic

past and firmly establishes the trajectory of PrEP and an imagined gay community who continues to be – but *at long last* will not always be – affected by HIV.

The documentary also depicts a particular affective community, comprised of radical activists who work collectively – within and outside of the formal state health system – towards a hopeful future. However, this future demands embodied forms of activism understood through biological citizenship – ingesting drugs to access drugs – in conjunction with a complex and *sometimes* cooperative health infrastructure. This version of the PrEP story requires the emergence of heroes – the ultimate biosexual citizens – and charts transformative journeys where the idealised 'good' sexual citizen (Richardson 2017) complies with the requirements of neoliberal health provision to be 'good' biological citizens. In contrast, the NHS – cast as the villain – is implicated in the denial of responsible gay citizens to exercise their rights, thereby steering them away from their hopeful futures. Yet this villainous figure is haunted by the complexity of austerity, rendering activism and enactments of citizenship as intimately entangled with the very health system with which they are also in battle.

Our analysis of *The People* illustrates the collective somatechnic entanglements of biotechnologies, activism and biosexual citizenship which are contingent on memories, bodies and hope: the narrative of biomedical success emerging from a shared traumatic past; establishing the body as a site of activism; and an orientation towards a hopeful future.

This work also adds to a growing body of humanities and social science scholarship on HIV activism through its consideration of PrEP imaginaries. Our exploration of how PrEP as a cultural object in community storytelling of activism, identity, and justice through visual texts offers important insight into contemporary HIV activism. Where the study of AIDS activism has focused largely on early responses and a continuity of community engagement

through archival research and oral testimonies of collective efforts (France 2016, Diedrich 2016, Lorway 2017), our work highlights how contemporary PrEP activist narratives within *The People* carefully depict a gay community affected by a traumatic past, but where individual access to biotechnological prevention through state – or private – provision is the end goal. Moreover, we expand PrEP scholarship beyond its current focus on lived experience of PrEP use or barriers to access; our reflections illustrate the ways in which HIV and community narratives shape PrEP imaginaries and open up – or close down – the somatechnic possibilities of PrEP through enactments and temporal orientations of biosexual citizenship. Jason Orne and James Gall (2019) describe how biosexual citizenship created through and around PrEP use helps to define – and to some extent re-imagine – sexual rights and responsibilities of queer men. We pay attention to community 'demands' of resource distribution from the state (Rose 2007) and how this is shaped by and requires enactments of biosexual citizenship which are temporally oriented through community histories as well as specific biomedical imperatives.

The People orients us towards the biomedical possibilities of eradication of HIV through PrEP. But for whom is this future? Ahmed argues that we ought to be attentive to the orientation of our hopefulness. Inequalities across class, race, and gender affect rates of HIV diagnoses and experiences of living with HIV in the UK, and early indications of the uptake of PrEP (Dolling et al. 2016) and recent decline in transmission rates (Public Health England 2017) in England suggest that HIV biomedicalisation is stratified (Shim 2010). As Dean (2011: 76) argues, it is necessary to be critical of the ideological ramifications of linear medical 'progress' narratives. In *The People*, campaigns about the individual's right to access PrEP, and the focus on its necessary health benefits, construct the availability and consumption of PrEP as an end goal to their activism. Rather than collective efforts towards prevention, access to PrEP is understood as an individual's right as a pharmaceutical

consumer. Accordingly, the NHS legal battle is foregrounded in the documentary, and access is portrayed as the ultimate objective and a destination celebrated as granting universal success. Here, PrEP, the 'miracle drug' and a symbol of hope, may sit within a nostalgic narrative in which scientific breakthrough prevails, and where 'white male heroes' (Cheng 2016) save many from their uncertain fate. This version of the story, however, does not challenge the existing social order, in which experiences of 'risk', transmission, and life with HIV are stratified. The linearity of the documentary's narrative arc positions particular behaviours as 'good' and 'bad' and particular outcomes as successful or otherwise, whilst editing out the complexities of PrEP. It is also important to pay attention to its silences: women, black and minority ethnic communities, and trans people rarely figure as key actors in the narrative, absences which continue to be mirrored in contemporary access to PrEP in the UK. In addition to the health benefits PrEP may offer some groups, our analysis raises critical questions about whether and how inequalities may also be upheld, deepened, and disguised, rather than alleviated, by these campaigns and the stories they often tell in wider PrEP imaginaries.

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