Politics, Protest, Emotion: Interdisciplinary Perspectives

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A Book of Blogs

Paul Reilly, Anastasia Veneti and Dimitrinka Atanasova (eds)

Information School, University of Sheffield

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Pre-exposure prophylaxis in the UK: Identity, stigma and activism

Rusi Jaspal, De Montfort University

Human Immunodeficiency Virus (HIV), which is the cause of Acquired Immune Deficiency Syndrome (AIDS), remains a major public health concern some 35 years after its first clinical observations. In the UK, men who have sex with men (MSM) are disproportionately affected by HIV. According to the Public Health England HIV Situation Report in 2015, approximately 43% of the 103700 individuals living with HIV in the UK are MSM, while 57% of the 5850 new HIV diagnoses (through sexual exposure) were within this demographic group. In London, it is estimated that 1 in 11 MSM is living with HIV. These epidemiological data suggest that existing HIV prevention methods, such as condom use, have not been entirely effective and that novel approaches are needed in the fight against HIV/AIDS.

This has led to discussions about the feasibility of pre-exposure prophylaxis (PrEP), which is a novel bio-medical approach for preventing HIV infection. The drug Truvada® (which consists of two nucleoside reverse transcriptase inhibitors, emtricitabine and tenofovir disoproxil fumarate) is currently used as PrEP in the US and was used in clinical trials in the UK. PrEP works by blocking a key enzyme that enables

HIV to replicate once it has entered a human CD4 t-lymphocyte. As HIV is unable to replicate, infection cannot occur. Various clinical trials in several populations suggest that PrEP is highly effective. Data from the UK PROUD study, for instance, indicated an 86% reduction in HIV infection among individuals in the experimental group taking Truvada. Truvada as PrEP can be taken either on a daily basis or "on-demand" (that is, before and after a possible exposure) in order to prevent HIV infection.

While PrEP has been available in the US since 2012, there is only limited access to PrEP in the UK. Following the promising data yielded in the UK PROUD study, NHS England began an economics evaluation in order to explore the cost effectiveness of offering the prevention tool on the National Health Service (NHS). In March 2016, NHS England decided not to commission PrEP, arguing that commissioning HIV prevention services is the responsibility of local authorities. In response to this decision, supporters of PrEP launched a petition calling for PrEP to be made available on the NHS. On the basis of robust scientific data, PrEP activists argue that the provision of PrEP would prevent thousands of new HIV infections among MSM, that is, it would reduce HIV incidence. Furthermore, despite concerns about the cost of funding PrEP, HIV prevention using PrEP is significantly less costly than life-long HIV treatment using ART. In view of these arguments and growing activism in favour of making PrEP available on the NHS, it is possible that NHS England will once again consider offering PrEP on the NHS.

Credit: incidence0.org

As PrEP is currently unavailable on the NHS, it can only be obtained

privately. The only sexual health clinic to provide access to PrEP is 56 Dean St (an NHS sexual health clinic located in Soho), which offers Truvada privately at a cost of £400 per month. As an alternative to Truvada, many MSM have been purchasing Tenvir-EM (a generic version of emtricitabine and tenofovir) online at a cost of approximately £45 per month. However, concerns have been raised about the authenticity (and, thus, effectiveness) of PrEP purchased online, as well as the wellbeing of patients whose condition (i.e. liver function) may not be consistently monitored by health care professionals. Indeed, this is concerning given that ART, such as emtricitabine and tenofovir, can cause serious side effects. In response to these concerns, several clinics in London, such as 56 Dean St and Mortimer Market Centre, now offer free PrEP clinics to monitor the condition of individuals who are purchasing PrEP privately. However, given the high cost of PrEP, uptake has been rather low and it is likely that many of those individuals most vulnerable to HIV infection do not have access to the prevention tool. Incidentally, in one US study, sexual risk-taking was associated with economic hardship, which suggests that those at highest risk may be financially unable to access PrEP. As an alternative to purchasing PrEP, there are also reports of "clinic hopping" which refers to the practice of visiting several sexual health clinics and falsely claiming to have been at risk of HIV in order to obtain post-exposure prophylaxis (PEP). As PEP usually consists of Truvada and a protease inhibitor or integrase inhibitor, the "clinic hopper" retains Truvada which can then be used as PrEP. The prevalence of this practice is not currently known but, as this constitutes a clandestine means of obtaining PrEP, the clinic hopper may not feel able to access the PrEP clinic.

In order to understand the underpinnings of activism around PrEP, it seems important to explore the social representations (that is, the images and constructions) of PrEP that have been emerging in the public domain. As the print media constitute a major source of societal information concerning science and medicine, we conducted an analysis of all of the articles published in UK national and regional newspaper outlets. This yielded a modest corpus of 57 articles, of which most were published in *The Independent* (20), *The Guardian* (13) and *The Daily Mail* (9). We

explored the tone of media reporting, and the major themes, tropes and metaphor drawn upon to describe PrEP. Overall, we identified two competing social representations of PrEP – the *hope representation*, on the one hand, and the *risk representation*, on the other. In creating the hope representation, metaphors of momentous change such as "revolutionary", "silver bullet", "the key" and "making history" were employed in relation to PrEP. These articles not only emphasised the positive characteristics of PrEP as an HIV prevention method, they also implicitly positioned it as being superior to existing methods, such as condom use and treatment as prevention (TasP). TasP refers to the virological suppression of the HIV-infected individual which reduces the likelihood of onward transmission. Furthermore, war metaphors such as "battle", "fight", "weapon" and "besieged" served to position PrEP as decisively changing the course of HIV prevention. Conversely, HIV was positioned as being weakened by PrEP. This pattern of media reporting tended not to acknowledge the potential shortcomings or limitations of PrEP, such as issues concerning toxicity, drug adherence and exposure to drug resistant strains of HIV. Conversely, the risk representation accentuated the risks and uncertainties associated with using PrEP and positioned the prevention tool as a hazard. This representation generally questioned the effectiveness of PrEP both in terms of the science of PrEP and the sexual attitudes and behaviours of gay and bisexual men which might serve to reduce the effectiveness of PrEP in this population. There was a clear element of social stigma in relation to gay sexuality and to the sexual practices said to be associated with this identity, which is echoed in a recent paper on "whore shaming" published in the *Journal of Homosexuality.* In short, sexual risk-taking and condom fatigue among gay and bisexual men were cited as key reasons why PrEP should be regarded as a risky HIV prevention method.

While the analysis suggested that the press appeared either to accentuate social stigma in relation to PrEP or to create unrealistic expectation vis-à-vis its effectiveness in eradicating HIV, the impact on public understanding was unclear, particularly among MSM, a group that is particularly likely to benefit the most from PrEP. Thus, in a separate study which is currently under review, I interviewed an ethnically diverse

sample of 20 HIV-negative and HIV-positive MSM to explore their perceptions and understandings of PrEP as well as their beliefs about how PrEP could impact their own lives and behaviours if it were to become available in the UK. HIV-negative MSM appeared to manifest uncertainty and fear in relation to PrEP as they believed that it would not be completely effective and that it would leave them feeling uncertain due to the "invisibility" of PrEP once it is taken (versus a condom which can be examined physically to ensure that it has remained intact during sex). Conversely, HIV-positive MSM were generally of the view that PrEP would reduce uncertainty and fear (primarily of onward transmission of HIV to HIV-negative partners). Similarly, there was a stark difference in how HIV-negative and HIV-positive MSM perceived the potential impact of PrEP on their interpersonal relations. While HIV-negative MSM felt that their use of PrEP could induce social stigma, HIV-positive MSM foresaw an improvement in relations with serodiscordant partners who they believed might feel less anxious about sex given the advent of PrEP. Although both cohorts acknowledged the possible benefits of PrEP, they nonetheless manifested stigma vis-à-vis the prevention tool, which led some HIV-negative MSM to reject PrEP for personal use.

It is clear that social stigma underpins attitudes towards PrEP both at social and individual levels. The prevalence of social stigma appears to have infiltrated thinking at an individual level, which has led individuals who may benefit from PrEP to reject it as an HIV prevention tool that people "at high risk" might utilise. This enables individuals to deflect from themselves the social stigma associated with PrEP. In response to social stigma and political inertia, social activism around PrEP has begun to emerge and it has taken shape in a number of ways. In general, activists have sought to educate others about PrEP in a bid to decrease stigma and, thus, to facilitate discussion.

As HIV campaigner Sadiq Ali indicated in his moving account of living with HIV, he was given the opportunity to take PrEP as part of the PROUD clinical trial but decided not to do so, because of the associated social stigma. A few weeks later, he contracted HIV. London-based writer, journalist and influential HIV equality campaigner, Greg Owen

describes a similar experience in relation to PrEP, which in part has led him to become a vocal advocate of the prevention tool, engaging in PrEP advocacy on a number of public platforms. His frank and candid accounts of gay sexuality and sexual risk-taking have contributed to breaking down the silence surrounding these very sensitive issues in public discourse. Indeed, Greg Owen's activism around PrEP has attracted considerable support among the HIV medical community. Greg Owen also co-founded the "I Want PrEP Now" website which seeks to provide "the information you need to understand and start taking PrEP in one place". Crucially, on the website individuals are informd about how to obtain PrEP online and how to access services vital to their wellbeing while on PrEP. PrEPster, another awareness-raising group formed "to educate and agitate for PrEP access in England and beyond", has similarly been campaigning for PrEP to become available on the NHS. The US-based Facebook group "PrEP Facts: Rethinking HIV Prevention and Sex" was founded by US psychotherapist Damon Jacobs in order "to support discussions, debates, questions, and concerns that promote fact-based information, understanding, respect, and compassion." The group now has over 14000 subscribers from all over the world, a paid editorial staff team, and consistent and lively discussion around the topic of PrEP. On the Facebook page, current PrEP users share their experiences of using PrEP and respond to others' queries about it.

It is important to note that these awareness-raising pressure groups have developed in online spaces, such as Twitter and Facebook, providing the perfect context in which to engage the public on the pressing issue of HIV prevention and, more specifically, on the role that PrEP might play in preventing HIV. This has facilitated collaborative work between US- and UK-based activists advocating for PrEP. The key challenges that PrEP activism engages with are social stigma and decreased public understanding of PrEP, both of which can inhibit public support for PrEP and ultimately lead to increased HIV incidence. Moreover, PrEP activists view social stigma and low awareness of PrEP as obstacles to making PrEP available on the NHS. The media have a key role to play in promoting a fair and balanced view of PrEP which is the ideal starting-point for a discussion about how PrEP ought to be implemented in

the UK. They at least *inform* the views and perceptions that individuals develop in relation to PrEP – stigma appears to be a key underlying theme. Stigma and silence will lead only to more HIV infections. PrEP activism must continue to decrease stigma and to facilitate dialogue.

Rusi Jaspal is Professor of Psychology and Sexual Health, Deputy Head of Research for the Faculty of Health and Life Sciences, and Deputy Director of the Mary Seacole Research Centre at De Montfort University Leicester. He is also a Chartered Scientist, Chartered Psychologist and a Fellow of the British Psychological Society, a Fellow of the Royal Society of Arts, and an Associate Fellow of the Higher Education Academy. His research focuses on the inter-relations between social representation, identity and social action. Rusi tweets at @ProfRJaspal.