

## Informal PrEP: an emerging need for nomenclature

Different expressions are used to describe the process of informal access to antiretroviral drugs (eg, via the Internet or acquaintances) for HIV pre-exposure prophylaxis (PrEP): “informal use”,<sup>1</sup> “informal PrEP”,<sup>2</sup> “off-label PrEP”,<sup>3</sup> “non-prescribed PrEP”,<sup>4</sup> “DIY PrEP”,<sup>5</sup> and “wild PrEP”.<sup>2</sup> This lack of consistent nomenclature makes it difficult to develop an accurate understanding of the nature of the process and its public health implications. To improve consistency for future research and public health initiatives, this process should be referred to as informal PrEP.

Informal use implies that PrEP could have been used incorrectly. Since only a few countries have approved Truvada (tenofovir disoproxil fumarate and emtricitabine; Gilead, Foster City, CA, USA) as PrEP, people have developed different techniques to access the molecules that make up Truvada, such as purchasing generic antiretroviral drugs online. However, although users might be using so-called informal channels, they might still be using PrEP correctly, with the supervision of a health-care professional, and be frequently tested for HIV and other sexually transmitted infections. In Canada and South Africa, for example, physicians were prescribing Truvada as PrEP before its official local approval. Characterised as off-label, this terminology is misleading since physicians can prescribe Truvada as PrEP based on the US Centers for Disease Control and Prevention (CDC) guidelines. In many countries, people can obtain a physician’s prescription for Truvada by asking for postexposure prophylaxis but using this treatment as PrEP, making the expression non-prescribed inaccurate.

Informal PrEP has various public health implications, which have already been addressed in the published literature.<sup>2</sup> Additional research is needed

to empirically assess its implications, both nationally and globally, and to understand the dynamics of its use. A consistent nomenclature would, we argue, facilitate such research and enable meta-analyses across different studies and jurisdictions. The term informal PrEP represents most accurately the process across its different public health dynamics. Although the term is not totally value-free, it is arguably less value-laden than other terms. Moreover, informal PrEP could better describe the fact that many people use PrEP correctly following the CDC guidelines but might be unable to access it through formal measures (eg, for financial reasons or policy barriers).

Adherence and rigorous medical surveillance through testing are essential for PrEP to work in HIV prevention, even more so for users of informal PrEP. A standard nomenclature can help support both research and advocacy for health policies to enable access to PrEP through formal channels (eg, a physician) that can ensure safety (eg, quality control of the drugs, and health monitoring).

JB reports grants, and a PhD scholarship from the Canadian Institutes of Health Research. VR and BW-J declare no competing interests.

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- 1 Zablotska IB, Prestage G, de Wit J, Grulich AE, Mao L, Holt M. The informal use of antiretrovirals for preexposure prophylaxis of HIV infection among gay men in Australia. *J Acquir Immune Defic Syndr* 2013; **62**: 334–38.
- 2 Brisson J. Ethical public health issues for the use of informal PrEP. *Glob Public Health* 2017; **13**: 1382–87.
- 3 Haire BG. Preexposure prophylaxis-related stigma: strategies to improve uptake and adherence—a narrative review. *HIV AIDS (Auckl)* 2015; **7**: 241–49.
- 4 Buttram ME, Kurtz SP. Preliminary evidence of HIV seroconversion among HIV-negative men who have sex with men taking non-prescribed antiretroviral medication for HIV prevention in Miami, Florida, USA. *Sex Health* 2016; **14**: 193–95.

- 5 Paparini S, Nutland W, Rhodes T, Nguyen VK, Anderson J. DIY HIV prevention: formative qualitative research with men who have sex with men who source PrEP outside of clinical trials. *PLoS One* 2018; **13**: e0202830.



Published Online  
December 18, 2018  
[http://dx.doi.org/10.1016/S2468-2667\(18\)30254-8](http://dx.doi.org/10.1016/S2468-2667(18)30254-8)