

PrEP from the bottom up: The role of grassroots advocates in the implementation of PrEP in Australia

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Introduction

By mobilising grassroots collectives and challenging established ways of working, HIV advocates have been instrumental in transforming the landscape of HIV treatment, prevention, and care. Similarly, community advocates have been important in supporting access to HIV pre-exposure prophylaxis (PrEP). We explore the role of PrEP advocacy groups in contributing to the rollout of PrEP in Australia

Methods

Multi-sited, ethnographic observations were conducted between November 2017 and July 2018 in Melbourne, and on the social media pages of two Australian-based PrEP advocacy groups. Interviews were conducted with PrEP advocates and researchers ($n=5$), PrEP users ($n=11$), and people living with HIV ($n=4$). Interviews and fieldnotes were analysed with a focus on the role of PrEP advocacy and the implementation of PrEP in Australia.

Findings

PrEP groups a source of support and resources

Recognising a gap in information about PrEP in Australia, individual gay community members established a digital presence to provide health resources to current and potential PrEP users, share information about demonstration trials, and crowdsource lists of PrEP-prescribing doctors. These groups were guided by a philosophy of sex-positivity and of countering stigmatising discourses around PrEP observed overseas:

“It’s important that we don’t hide. It [PrEP] needs to be visible and public, and there’s nothing dodgy or shameful about it”

- Tim, PrEP advocate

“We were also concerned about, having been exposed to the US experience, the stigma that PrEP users were experiencing ... But also wanted to promote positive sex messages, sex positivity”

- Luke, PrEP advocate

Facilitation of PrEP self-importation

PrEP advocates were instrumental in establishing a relationship with an overseas pharmacy to facilitate access to generic PrEP medications for those unable to access PrEP through state-based implementation trials. Recognising cost as a potential barrier, advocates also negotiated an assistance scheme to provide subsidised or free PrEP to those unable to afford it, regardless of Medicare eligibility.

“[We wanted] to get PrEP into the hands of people who weren’t in a study and who couldn’t afford it.

- Luke, PrEP advocate

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Synergy between researchers and advocates

A key aspect of the work of PrEP advocates was establishing relationships with PrEP researchers and community organisations. This enabled those working at the research and policy level to gain insight into community attitudes and concerns, almost in real time:

“I need to hear from [PrEP advocates] because I can go and talk at scientific meetings about intimacy and sexuality and anecdotally how people are feeling on PrEP ... I find it’s sort of a camaraderie, we’re all in it together ... If you get the community involved, man it makes all the difference”

- Sam, PrEP & HIV researcher

Far from information flowing only from grassroots to the institutional level, a reciprocal relationship was established whereby PrEP advocates gained insight into developments in new and ongoing PrEP implementation trials:

“Through that kind of alliance, we’ve all had open communication. So we haven’t needed to advocate or kind of demand anything, because we’ve always been involved in the communication to know that, hey, it’s coming anyway”

- Tim, PrEP advocate

Conclusion

Australian PrEP advocacy groups mobilised community resources, social media, and lay expertise to improve PrEP accessibility and productively shape the Australian rollout and public framing of PrEP. These groups were crucial in providing resources on and access to PrEP, including free PrEP medications for those who were Medicare ineligible or could not afford PrEP. As new PrEP technologies emerge, COVID-19 and monkeypox reshape patterns of sex and access to healthcare, and as PrEP access continues to be inaccessible for some key populations, the expertise and networks of these groups can be leveraged to sustain PrEP coverage and continue Australia’s successful HIV response.

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