



HAL
open science

Community engagement in the provision of culturally competent HIV and STI prevention services: lessons from the French experience in the era of PrEP

Daniela Rojas Castro, Rosemary Delabre, Stéphane Morel, David Michels, Bruno Spire

► To cite this version:

Daniela Rojas Castro, Rosemary Delabre, Stéphane Morel, David Michels, Bruno Spire. Community engagement in the provision of culturally competent HIV and STI prevention services: lessons from the French experience in the era of PrEP. *Journal of the International AIDS Society*, 2019, 22 (S6), 10.1002/jia2.25350 . hal-02612017

HAL Id: hal-02612017

<https://amu.hal.science/hal-02612017v1>

Submitted on 18 May 2020

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution 4.0 International License

VIEWPOINT

Community engagement in the provision of culturally competent HIV and STI prevention services: lessons from the French experience in the era of PrEP

Daniela Rojas Castro^{1,2§*} , Rosemary M Delabre^{1*} , Stéphane Morel^{1,3}, David Michels^{1,3} and Bruno Spire^{1,2,3} 

§**Corresponding author:** Daniela Rojas Castro, Coalition PLUS, Community-Based Research Laboratory, 14 rue Scandicci, 93500 Pantin, France. Tel: +33 6 99 17 69 40. (drojascastro@coalitionplus.org)

Keywords: community; community-based research; HIV prevention; key and vulnerable populations; PrEP; STI

Received 24 May 2019; Accepted 24 June 2019

Copyright © 2019 The Authors. *Journal of the International AIDS Society* published by John Wiley & Sons Ltd on behalf of the International AIDS Society. This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Communities have been a driving force in the response to the HIV epidemic, advocating for research, the access to treatment and healthcare, and human rights for key populations (KP) and people living with HIV (PLHIV). The importance of community engagement (CE) in the development and implementation of pertinent programmes throughout the HIV care continuum has been widely recognized [1-3]. In the context of increasing pre-exposure prophylaxis (PrEP) research, interest and access (though still limited), there is an opportunity to have a fresh look at CE regarding HIV/STI research and care delivery. France, where PrEP has been authorized and fully reimbursed since 2016, may provide key lessons for CE in the provision of comprehensive, culturally adapted HIV/STI prevention and treatment services.

Community involvement in HIV/AIDS is political and ethical. Community-based organizations (CBOs) such as Gay Men's Health Crisis (US), Terrence Higgins Trust (UK), the Grupo Pela Vidda (Brazil), AIDES (France), or international organizations such as ACT-UP, have historically played important roles in advocating for suitable information on prevention tools and adequate access to health for PLHIV and most-at-risk populations [2-4]. PrEP research is not an exemption [5]. For example, Act Up-Paris and others advocated for the early termination of two PrEP studies due to, among other reasons, the lack of medical services for those who seroconverted on study [6-9]. While implementation of "Good Participatory Practice Guidelines" [10,11] and community advisory boards [12] in research studies are steps forward, further effort is needed to ensure more meaningful CE throughout the entire life course of research studies [13,14]. For example, by building the evidence-base for CE and evaluating its success in meeting community needs [15].

In 2008, AIDES adopted a unique strategy to invest financial and human resources for the creation of a community-based research unit. Working in partnership with research institutions and funding bodies, community-based studies have

identified community needs and contributed to the development of innovative and adapted services: rapid HIV testing, educational sessions for injection drug users, and PrEP counselling.

While medical providers may lack the time, skill and/or motivation to address sexual health issues [16,17], CBOs are well-placed to identify the sexual health needs of KP and provide comprehensive and adapted care [18]. The Fenway Community Health Center in Boston provides comprehensive "culturally competent" care [19]. The 56 Dean Street clinic in London offers a successful well-being programme and an "express" service for self-sampling HIV and STI tests [20]. In Bamako, the CBO ARCAD-SIDA's night sexual health clinic provides testing and treatment services for MSM and sex workers [21]. Finally, results of a community-based testing satisfaction survey conducted by AIDES [22] partially led to the creation of two community-based sexual health structures that integrate sexual and mental health consultations (SPOT Beaumarchais in Paris and SPOT Longchamp in Marseille). Community-based clinical programmes are important examples of how communities and medical professionals may work together to develop and provide effective services.

PrEP provision is an opportunity to provide comprehensive sexual health services, engage individuals on their needs, and to equip them to better evaluate and reduce their HIV/STI risk. AIDES has been a full partner in two PrEP studies: ANRS-Ipergay [23] and ANRS-Prévenir [24,25]. Peer counselling, provided by AIDES counsellors, was constructed collectively with social science researchers (GRePS and Inserm). Based upon individual needs and expectations, discussions go beyond purely medical aspects regarding PrEP to include questions such as "What risks can you identify related to your sex life?" and "Is your sex life as fulfilling as you would like?." Therefore, PrEP is not an end in itself, but rather an opportunity to empower communities regarding sexual health.

As PrEP protects from HIV but not STIs, appropriate and adapted risk reduction methods such as prophylactic antibiotics [26] should be considered. Follow-up appointments, required in the provision of PrEP, allow for STI information, regular screenings and early treatment. However, this regular hospital medical follow-up can represent a barrier, and respondents to a European community-based survey felt that PrEP should be available at community-based health settings or at the general practitioners' [27]. Provision of HIV and STI services outside of traditional medical structures is essential to reach populations who are most exposed and face access barriers. Community-based initiatives such as community-based testing have reached at-risk populations as well as those who have never been tested [18,28] and have identified individuals at an earlier disease stage [29]. More innovative partner notification strategies, such as Check-Out™ developed by the Checkpoint LX in Portugal [30], may be used in the context of PrEP [25].

All communities particularly affected by HIV and STIs must be involved in the development of adapted and inclusive information and programmes regarding provision of PrEP and/or other services (e.g. PEP, STI prophylaxis) which reach KP other than MSM. Regarding transgender people, for example, concerns related to finding "trans-competent" providers and potential interaction with hormones should be addressed [31]. The Thai Red Cross Tangerine Health Center is one example of a community-engaged model providing comprehensive services for transgender women [32]. Women may experience barriers to PrEP, indicating a need for adapted services. Several community-based initiatives are increasingly providing tailored PrEP information to increase awareness among women [33,34]. CE is also critical for the development of adapted and sustainable prevention programmes among sex workers [35,36]. Finally, it is necessary to address stigma related to sexual preferences, drug use, sex work and PrEP use [37-39].

Communities have the knowledge, skills and motivation to provide culturally adapted information and services for PLHIV and KP. Community-based initiatives can and must go further. For example, community-based ART delivery, already implemented in some southern countries [40], needs to be expanded to northern countries. Partnerships between communities and traditional health structures will require the support of governments and international bodies to implement and enforce policies for task shifting in addition to significant funding. We call for a united effort amongst government bodies, health providers, and CBOs to make a comprehensive, positive approach to sexual health for PLHIV and for those most exposed to HIV a reality.

AUTHORS' AFFILIATIONS

¹Coalition PLUS, Community-Based Research Laboratory, Pantin, France; ²Aix Marseille Univ, INSERM, IRD, SESSTIM, Sciences Economiques & Sociales de la Santé & Traitement de l'Information Médicale, Marseille, France; ³AIDES, Pantin, France

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

BS, DRC, RMD, SM and DM conceptualized the commentary. SM and DM provided content on AIDES' community-based approach and activities. BS, DRC, RMD, SM and DM discussed key ideas and concepts forming the basis of this

commentary. RMD and DRC reviewed the literature and wrote the manuscript. All authors reviewed and approved the final version.

ACKNOWLEDGEMENTS

We thank all those PLWHA and KP who continue to challenge ideas and policies that are stigmatizing and/or discriminatory and fight for equal and just human rights. We would also like to thank the following for their continued support for community-based research: France Recherche Nord&Sud Sida-hiv Hépatites (ANRS), Assistance Publique – Hôpitaux de Paris (AP-HP), Sciences Economiques & Sociales de la Santé & Traitement de l'Information Médicale (SESSTIM), GRePS and Prof. Jean-Michel Molina.

REFERENCES

1. UNAIDS. The essential role of civil society. Report on the Global AIDS Epidemic. A UNAIDS 10th Anniversary Special Edition. Geneva; 2006. 202–22.
2. Trapence G, Collins C, Avrett S, Carr R, Sanchez H, Ayala G, et al. From personal survival to public health: community leadership by men who have sex with men in the response to HIV. *Lancet*. 2012;380(9839):400–10.
3. Merson MH, O'Malley J, Serwadda D, Apisuk C. The history and challenge of HIV prevention. *Lancet*. 2008;372(9637):475–88.
4. Aggleton P, Pedrosa JS. Community, solidarity and action—grupo pela VIDA, Brazil. *AIDS Care*. 1994;6(3):343–8.
5. Sugarman J, Mayer KH. Ethics and pre-exposure prophylaxis for HIV-infection. *J Acquir Immune Defic Syndr*. 2013;63:S135–9.
6. Ahmad K. Trial of antiretroviral for HIV prevention on hold. *Lancet Infect Dis*. 2004;4(10):597.
7. Forbes A, Mudaliar S. Preventing Prevention trial failures: a case study and lessons for future trials from the 2004 tenofovir trial in Cambodia [Internet]. Global Campaign for Microbicides; 2009 [cited 2018 Dec 19]. Available from: <https://path.org/resources/preventing-prevention-trial-failures-a-case-study-and-lessons-for-future-trials-from-the-2004-tenofovir-trial-in-cambodia/>
8. Singh JA, Mills EJ. The abandoned trials of pre-exposure prophylaxis for HIV: what went wrong? *PLoS Med*. 2005;2(9):e234.
9. McGrory E, Irvin A, Heise L. Research rashomon: lessons from the Cameroon pre-exposure prophylaxis trial site [Internet]. Global Campaign for Microbicides; 2009 [cited 2018 Dec 19]. Available from: <https://www.path.org/resource/s/research-rashomon-lessons-from-the-cameroon-pre-exposure-prophylaxis-trial-site/>
10. UNAIDS, AVAC. Good participatory practice guidelines for biomedical HIV prevention trials. 2007.
11. UNAIDS, AVAC. Good Participatory Practice (GPP) Guidelines. 2011.
12. Morin SF, Morfit S, Maiorana A, Aramrattana A, Goicochea P, Mutsambi JM, et al. Building community partnerships: case studies of Community Advisory Boards at research sites in Peru, Zimbabwe, and Thailand. *Clin Trials Lond Engl*. 2008;5(2):147–56.
13. Day S, Blumberg M, Vu T, Zhao Y, Rennie S, Tucker JD. Stakeholder engagement to inform HIV clinical trials: a systematic review of the evidence. *J Int AIDS Soc*. 2018;21(S7):e25174.
14. Fregonese F. Community involvement in biomedical research conducted in the global health context; what can be done to make it really matter? *BMC Med Ethics* [Internet]. 2018 Jun 15 [cited 2019 May 13];19 Suppl 1. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6019999/>
15. MacQueen KM, Bhan A, Frohlich J, Holzer J, Sugarman J; Ethics Working Group of the HIV Prevention Trials Network. Evaluating community engagement in global health research: the need for metrics. *BMC Med Ethics*. 2015;16:44.
16. Carter JW, Hart-Cooper GD, Butler MO, Workowski KA, Hoover KW. Provider barriers prevent recommended sexually transmitted disease screening of HIV-infected men who have sex with men. *Sex Transm Dis*. 2014;41(2):137–42.
17. Hoover KW, Butler M, Workowski K, Carpio F, Follansbee S, Gratzner B, et al. STD screening of HIV-infected MSM in HIV clinics. *Sex Transm Dis*. 2010;37(12):771–6.
18. Champenois K, Le Gall J-M, Jacquemin C, Jean S, Martin C, Rios L, et al. ANRS-COMTEST: description of a community-based HIV testing intervention in non-medical settings for men who have sex with men. *BMJ Open* [Internet]. 2012 [cited 2018 Dec 21];2(2). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3323802/>
19. Mayer K, Appelbaum J, Rogers T, Lo W, Bradford J, Boswell S. The evolution of the Fenway Community Health model. *Am J Public Health*. 2001;91(6):892–4.
20. Kirby T, Thornber-Dunwell M. Dean Street clinics-battling London's MSM HIV epidemic. *Lancet HIV*. 2018;5(5):e210.

21. Coulibaly A, Dembelé Keita B, Henry E, Trenado E. Faciliter l'accès aux soins des populations les plus exposées: l'expérience de la clinique nocturne de santé sexuelle de Bamako au Mali. *Promot Santé En Afr*. 2014;Juillet:67–70.
22. Rios L, Rojas Castro D, Quatremère G, Monvoisin D, Fugon L, Tessier S, et al. Enquête d'opinion sur la qualité d'offre de dépistage communautaire de l'association AIDES et autres attentes de services de santé sexuelle. Poster presentation at: AFRAVIH; 2014; Montpellier, France.
23. Molina J-M, Capitant C, Spire B, Pialoux G, Cotte L, Charreau I, et al. On-demand preexposure prophylaxis in men at high risk for HIV-1 infection. *N Engl J Med*. 2015;373(23):2237–46.
24. ANRS. L'étude ANRS Prévenir démarre [Internet]. 2017 [cited 2019 Jan 7]. Available from: <http://www.anrs.fr/fr/actualites/313/letude-anrs-prevenir-demarre>
25. Morel S. Promoting sexual health through community education and activism: How community involvement could improve sexual health access & STI test regularity. Presentation at: STI 2018: Understanding and Addressing the HIV and STI Syndemics; 2018; Amsterdam, The Netherlands.
26. Molina J-M, Charreau I, Chidiac C, Pialoux G, Cua E, Delaugerre C, et al. Post-exposure prophylaxis with doxycycline to prevent sexually transmitted infections in men who have sex with men: an open-label randomised substudy of the ANRS IPERGAY trial. *Lancet Infect Dis*. 2018;18(3):308–17.
27. Bernier A, Delabre R, Schlegel V, Vilotitch A, Ghosn J. What role might general practitioners play in pre-exposure prophylaxis programs in Europe? Results from a 2016 European community-based survey "Flash PrEP in Europe" (FPIE). Poster presented at: 16th European AIDS Conference; 2017; Milan, Italy.
28. Fernández-López L, Reyes-Urueña J, Agustí C, Kustec T, Klavs I, Casabona C. The COBATEST network: a platform to perform monitoring and evaluation of HIV community-based testing practices in Europe and conduct operational research. *AIDS Care*. 2016;28(sup1):32–6.
29. Suthar AB, Ford N, Bachanas PJ, Wong VJ, Rajan JS, Saltzman AK, et al. Towards universal voluntary HIV testing and counselling: a systematic review and meta-analysis of community-based approaches. *PLoS Med*. 2013;10(8):e1001496.
30. Rocha M, Guerreiro R, Pinto N, Rojas J, Ferreira F, Esteves J, et al. Digital Partner Notification Service at a Community-based Voluntary Counselling and Testing Centre for Men Who Have Sex with Men: Checkpoint LX, Lisbon, Portugal. Poster presentation at: 21st International AIDS Conference (AIDS2016); 2016; Durban.
31. Sevelius JM, Keatley J, Calma N, Arnold E. 'I am not a man': trans-specific barriers and facilitators to PrEP acceptability among transgender women. *Glob Public Health*. 2016;11(7–8):1060–75.
32. Janamnuaysook R. The Importance of Trans Comprehensive Health Services to the HIV Responses: Lessons Learned from TANGERINE Community Health Center [Internet]. 2019 Apr 24 [cited 2019 May 13]. Available from: <http://www.wearaptn.org/2019/04/24/the-importance-of-trans-comprehensive-health-services-to-the-hiv-responses-lessons-learned-from-tangerine-community-health-center/>
33. Women and PrEP. Women and PrEP [Internet]. 2019 [cited 2019 Jun 22]. Available from: <http://womenandprep.org.uk/>
34. Boerner H. To Halt HIV, Advocates Push For PrEP Outreach To Black Women [Internet]. NPR.org. 2019 [cited 2019 Jun 22]. Available from: <https://www.npr.org/sections/health-shots/2019/02/08/691740052/to-halt-hiv-advocates-push-for-prep-outreach-to-black-women>
35. Bekker L-G, Johnson L, Cowan F, Overs C, Besada D, Hillier S, et al. Combination HIV prevention for female sex workers: what is the evidence? *Lancet*. 2015;385(9962):72–87.
36. Shannon K, Crago A-L, Baral SD, Bekker L-G, Kerrigan D, Decker MR, et al. The global response and unmet actions for HIV and sex workers. *Lancet Lond Engl*. 2018;392(10148):698–710.
37. Spire B, de Zoysa I, Himmich H. HIV prevention: what have we learned from community experiences in concentrated epidemics? *J Int AIDS Soc*. 2008;11:5.
38. Pinto RM, Berringer KR, Melendez R, Mmeje O. Improving PrEP implementation through multilevel interventions: a synthesis of the literature. *AIDS Behav*. 2018;22(11):3681–91.
39. Sawicki DA, Meffert BN, Read K, Heinz AJ. Culturally competent health care for sex workers: an examination of myths that stigmatize sex-work and hinder access to care. *Sex Relatsh Ther* [Internet]. 2019 Feb 19 [cited 2019 Jun 23]. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6424363/>
40. Decroo T, Rasschaert F, Telfer B, Remartinez D, Laga M, Ford N. Community-based antiretroviral therapy programs can overcome barriers to retention of patients and decongest health services in sub-Saharan Africa: a systematic review. *Int Health*. 2013;5(3):169–79.