



## PrEP Works, But Only When You [Have Access to] Take it: Improving PrEP Access for Young People in Chicago and Philadelphia

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The 2012 United States Food and Drug Administration approval of Tenofovir/Emtricitabine for HIV pre-exposure prophylaxis (PrEP) has added a highly effective, safe biomedical option to the HIV prevention toolbox. In the United States, young black and Latino men who have sex with men (MSM) and transgender women are disproportionately affected by HIV risk over the course of their lifetime [1]. Nearly 1 in 10 black MSM under age 25 is infected with HIV every year [2], and there are more new HIV infections among young MSM of color ages 13 to 30 than in any other age or racial group [3]. The proven efficacy of PrEP, when taken daily, in real-world clinical settings among high-risk adult populations demonstrates that this tool has the potential to change the course of the HIV epidemic [4]; however, the unique needs of a youth population and the importance of co-locating comprehensive, one-stop services for young people remain conspicuously absent from conversations about models of PrEP delivery and implementation.

Access to care is the opportunity or ease with which patients or communities are able to use appropriate services in proportion to their needs [5], which encompasses significantly more than an individual's ability to find affordable care. The ubiquitous catch phrase for pre-exposure prophylaxis (PrEP) for HIV prevention seems to have become- "*PrEP works, but only if you take it*" While this phrase is accurate, one must not forget that access to taking the medication in a setting that is both competent and affirming of patients' identities and healthcare needs is the necessary first step to ensuring good adherence. This commentary outlines five key elements of a low-barrier model for PrEP delivery and implementation in two clinical settings that have been recognized for high rates of retention and medication adherence [6]: the Youth Health Empowerment Project (Y-HEP), a program of Philadelphia FIGHT in Philadelphia and the Broadway Youth Center (BYC), a program of Howard Brown Health in Chicago. Y-HEP and BYC are youth drop-in centers that offer a safe space for young people ages 12 (BYC) or 13 (Y-HEP) to 24 to access healthcare and other social support services. Both programs provide PrEP in the context of comprehensive primary and sexual healthcare settings that uniquely address the needs of young queer and transgender patients. These two programs provide care to predominantly lesbian, gay, bisexual, transgender, queer and gender non-conforming youth and young adults of color. Y-HEP currently has 133 young MSM and transgender women enrolled in the PrEP program, and BYC currently has 28.

1. Trauma-informed approach to care: Patients served by Y-HEP and BYC, as members of highly marginalized communities, have experienced a significant amount of trauma in childhood and/or adolescence that may include sexual or physical abuse, emotional abuse, neglect, witness to domestic or community violence, or traumatic separation from a family member. Both centers address and tailor approaches to care and respond to the unique needs of patients with trauma histories in order to provide support that recognizes the emotional, spiritual, physical impact of trauma. Both clinical and non-clinical staff are trained to recognize and remain sensitive to the ways in which trauma can negatively affect health outcomes and engagement in care. Formal and informal trainings emphasize critical elements of a trauma-informed approach to care, including 1) maximizing a patient's sense of safety, 2) discussing health care and prevention in language that does not trigger overwhelming emotion or fear, 3) setting firm personal-professional boundaries while maintaining consistency and trust over time, 4) maintaining a body-positive sex-positive gender-affirming environment, and 5) coordinating care with other agencies that can provide supportive services.

2. Situated within a comprehensive youth-friendly social support program: Both programs are committed to assisting young people to enter PrEP care and remain engaged in care by helping to meet a diverse set of needs in their lives. At these sites, PrEP and HIV prevention clinical services were added to pre-existing youth-friendly drop-in settings that provide a broad range of services to young people. Both programs have resources to support patients who are homeless and/or housing insecure through access to a safe space, food, laundry, clothing, and skill building workshops. Y-HEP and BYC also offer counseling and therapy services, and full primary and sexual healthcare on-site. Moreover, each site has counselors with whom a young person can meet one-on-one to enroll in any number of benefits, including Supplemental Nutrition Assistance Program (SNAP), housing assistance, or health insurance. Our commitment stems from a belief that youth and young adults continue to make healthy choices if other critical needs are being addressed on an ongoing basis.

3. Belief in youths' ability to take PrEP: Both BYC and Y-HEP's PrEP programs were early adopters and providers of PrEP to young people in Chicago and Philadelphia, and from the onset have focused

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on harm reduction principles and promoting youth as agents in their own care. This approach stems from a long history of providing care to youth and adults living with HIV in settings that emphasize patient empowerment and the importance of working within communities to combat stigma and promote self-efficacy with respect to taking HIV medications. As such, the BYC and Y-HEP programs - at the core - have always believed that youth and young adults could successfully take PrEP as HIV prevention and that the programs must determine how to best support them to succeed rather than determine whether they will or will not succeed. Staff work with patients to create medication pick-up schedules and adherence plans that recognize the complexities of their lives and needs, and medications are delivered directly to these centers from different pharmacies (patients can also pick medications up from a local pharmacy if they choose) so that youth can pick them up at the same time as they access other services or get follow-up laboratory testing. At Y-HEP, young people have the option to come to clinic daily for directly observed therapy, weekly, biweekly, monthly or every three months to pick up their PrEP. Clinical visit and medication pick-up appointments are scheduled but flexible, such that if patients miss a scheduled visit, they receive a text message reminder to come in later in the week. Both BYC and Y-HEP utilize an adherence plan tool (Appendix 1) that facilitates conversations with providers - clinicians, benefits counselors, or medical assistants and encourages a team approach to adherence. BYC works with patients to see them monthly or every three months.

4. Staff advocate on behalf of youth for medication access: Often, youth and young adults experience a great deal of frustration when they are ready to initiate PrEP and are then confronted with cumbersome insurance road blocks. As advocates for young people, it is important that clinic staff have the ability and accountability to navigate these waters for PrEP users. Both agencies are committed to the idea that PrEP access and health care for young people should be free (Appendix 2). For the majority of young people coming into Y-HEP and BYC, support staff are able to access medication for insured and uninsured patients with almost no cost to the patient as a result of a variety of resources available to clinics in the United States (Appendix 2). Staff at both clinics must take on the role of advocate when speaking to pharmacies and medication access programs to ensure that patients are able to fill their prescriptions.

5. Innovative policies: Both clinics have been advocates for supporting young people ages 12 - 24 in PrEP access and have developed policies for providing PrEP to individuals under age 18 without parental consent when consent cannot reasonably or safely be obtained. These policies draw upon other well-accepted precedents of providing care to minors without parental consent (HIV treatment, sexually transmitted disease screening and treatment, care of a pregnant minor, etc.) and list clear criteria under which PrEP may be prescribed to patients under age 18 in the absence of parental consent. These policies have been helpful in providing a legal framework for provision of under-18 care when the risks of requiring parental consent outweigh the benefits; however, this policy cannot be used when caring for patients who are wards of the Department of Health

Services (DHS). Both clinics have also established policies that codify same-day PrEP initiation in recognition that the more traditional starting recommendations (check labs and start PrEP a few days later or at next visit once labs have been reviewed with patient) may lead to lost opportunities to retain young patients in care and protect them imminently against HIV. Third, Y-HEP has a large city-wide HIV testing program that links patients who test negative to the PrEP program, and both programs offer post-exposure prophylaxis (PEP) for high-risk HIV exposures that can subsequently be "rolled over" to PrEP. Lastly, the Y-HEP PrEP program has developed a lab-based urine tenofovir (TFV) assay that objectively monitors adherence to Truvada™ as PrEP [7]. In the subset of 50 patients enrolled in this study, patients are informed of the results of urine testing as part of ongoing adherence support; 70-80% of the subjects in this cohort have urine tenofovir levels that are consistent with high-level adherence to PrEP (data not reported, study nearing completion).

Sufficient adherence to PrEP cannot be achieved in youth (the population in which the rate of new HIV infections is growing the fastest, and simultaneously the population that has been historically the most difficult to access) without committing to provision of easily accessed, youth-centered healthcare. For agencies similar to ours - community-based organizations that serve youth and young adults with active clinical, social support, and research programs - we recommend instituting similar initiatives to increase accessible PrEP care for high-risk youth as many of these elements can be implemented through changes in organizational practices and emphasis on staff training at relatively low cost. Further work will need to be done to determine best practices in other settings in the US and globally.

## References

1. Hess K, Hu X, Lansky A, Mermin J, Hall HI (2016) Estimating Lifetime Risk of a Diagnosis of HIV Infection in the United States. CROI 2016, Boston, MA, USA.
2. Rosenberg ES, Sullivan PS, Kelley CF, Sanchez Th, Luisi N, et al. Race and age disparities in HIV incidence and prevalence among MSM in Atlanta, GA, Conference on Retroviruses and Opportunistic Infections; Boston, MA 2014.
3. Centers for Disease Control and Prevention (CDC) (2008) Subpopulation estimates from the HIV incidence surveillance system—United States, 2006. See comment in PubMed Commons below MMWR Morb Mortal Wkly Rep 57: 985-989.
4. Volk JE, Marcus JL, Phengrasamy T, Blechinger D, Nguyen DP, et al. (2015) No New HIV Infections with Increasing Use of HIV Preexposure Prophylaxis in a Clinical Practice Setting. Clin Infect Dis 61:1601-1603.
5. Daniels N (1982) Equity of access to health care: some conceptual and ethical issues. See comment in PubMed Commons below Milbank Mem Fund Q Health Soc 60: 51-81.
6. Conyngham SC, Sloan CE, Warren C, Pohl D, Koenig HC: PrEP Works, but Only When You [Have Access To] Take It: Improving PrEP Access for Young People in Chicago and Philadelphia. Presented as an oral abstract at the CDC National HIV Prevention Conference, Atlanta, GA December 2015.
7. Koenig HC, Tebas P, Mounzer K, Daughtridge GW, Sloan CE, et al. (2015) Urine Assay for Tenofovir to Monitor Adherence to Tenofovir/Emtricitabine as PrEP, Abstract 975 presented at the Conference on Retroviruses and Opportunistic Infections, Boston, MA.