Original article

Linking HIV-Negative Youth to Prevention Services in 12 U.S. Cities: Barriers and Facilitators to Implementing the HIV Prevention Continuum

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A B S T R A C T

Purpose: Linkage of HIV-negative youth to prevention services is increasingly important with the development of effective pre-exposure prophylaxis that complements behavioral and other prevention-focused interventions. However, effective infrastructure for delivery of prevention services does not exist, leaving many programs to address HIV prevention without data to guide program development/implementation. The objective of this study was to provide a qualitative description of barriers and facilitators of linkage to prevention services among high-risk, HIV-negative youth. Design: Thematic analysis of structured interviews with staff implementing linkage to prevention services programs for youth aged 12–24 years.
Methods: Twelve adolescent medicine HIV primary care programs as part of larger testing research program focused on young sexual minority men of color. The study included staff implementing linkage to prevention services programs along with community-based HIV testing programs. The main outcomes of the study were key barriers/facilitators to linkage to prevention services.
Results: Eight themes summarized perspectives on linkage to prevention services: (1) relationships with community partners, (2) trust between providers and youth, (3) youth capacity to navigate prevention services, (4) pre-exposure prophylaxis specific issues, (5) privacy issues, (6) gaps in health records preventing tailored services, (7) confidentiality of care for youth accessing services through parents'/caretakers' insurance, and (8) need for health-care institutions to keep pace with models that prioritize HIV prevention among at-risk youth. Themes are discussed in the context of factors that facilitated/challenged linkage to prevention services.
Conclusions: Several evidence-based HIV prevention tools are available; infrastructures for co-ordinated service delivery to high-risk youth have not been developed. Implementation of such infrastructures requires attention to community-, provider-, and youth-related issues.
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IMPLICATIONS AND CONTRIBUTION

Although linkage of HIV-negative youth to prevention services is increasingly important with growing utilization of pre-exposure prophylaxis along with behavioral and other prevention-focused interventions, effective infrastructure for delivery of prevention services is underdeveloped. The current study reports themes on barriers and facilitators to creation of such an infrastructure.

The HIV Prevention Continuum differs from the better known HIV Continuum of Care for HIV-positive youth in its emphasis on prevention among high-risk HIV-negative individuals, connecting HIV testing to a youth-friendly infrastructure for long-term prevention services (including pre-exposure prophylaxis [PrEP]), with retention of these youth over time to reinforce prevention behaviors, to intervene in lapses of prevention behaviors, and to identify early incident infections [1–3]. Current research and policy only address the initial step of the Prevention Continuum—HIV testing [1–6]. Ideally, each testing event is a prevention opportunity, either by linking HIV-positive youth to treatment services, or by linking HIV-negative youth to prevention services [1,5,7]. Evidence-based best practices for linkage to care for youth testing positive are increasingly well described [8–10].

However, systematic, community-focused approaches of linkage to prevention services for youth—following a negative HIV test—are not well described. Practically speaking, infrastructure for such comprehensive HIV prevention services does not exist. For example, PrEP, as a biomedical prevention intervention, requires linkage—preferably at the time of testing—to a youth-friendly health-care provider capable of prescribing and monitoring medications [5,7]. Other prevention services are not necessarily associated with PrEP provision. For example, screening, brief intervention, referral, and treatment for mental health and substance use are not an automatic concomitant of PrEP prescription and monitoring. Clinics providing PrEP could also provide evidence-based interventions to reduce HIV-related behavioral risks [11], but such interventions are peripheral to the clinical requirements for determining indications for a medication, prescription to eligible patients, and monitoring effectiveness and side effects.

Legal and ethical barriers further complicate implementation of HIV prevention services for minors. Currently, only a few states expressly permit minor consent for sexually transmitted infections (STIs) and HIV prevention services [9], leaving the majority of youth without access to prevention services in the absence of parental permission. Barriers to legal access profoundly impact youths' use of prevention services [10]. The bottom line is that no well-defined approach exists for provision of HIV prevention services—especially PrEP—for at-risk youth [12,13].

The research presented here describes the systematic implementation of programs—as part of a larger community-based testing and prevention program—for linkage to prevention services for youth, aged 13–24 years who are at risk but are HIV negative. The community-based strategies for HIV testing and linkage to health care for HIV-positive youth are described elsewhere [2]. Our objective was to provide guidance toward the implementation of community-based, comprehensive HIV prevention services for youth.

Methods

To address the legal, ethical, and public health challenges of comprehensive HIV prevention services for youth, we implemented a pilot demonstration project named Connect to Test and Prevent (C2TaP). C2TaP was a multisite implementation science project to identify the processes and strategies by which at-risk youth were tested for HIV, with linkage to prevention services for those who tested negative. The sites were located in urban, resource-challenged communities with high HIV burden. Within each community, we built upon stakeholder networks developed in prior research, including Connect to Protect (C2P, the HIV prevention community mobilization efforts of the Adolescent Trials

for HIV/AIDS Prevention Interventions [ATN]) and the Strategic Multisite Initiative for the Identification, Linkage and Engagement (SMILE) in care of HIV-infected youth demonstration project designed to connect newly infected youth to youth-friendly HIV care [14,15]. Further, C2TaP incorporated four principles of implementation science: (1) understanding the implementation environment; (2) observing the process of implementation; (3) testing implementation approaches; and (4) linking implementation evidence to policy, larger program design, and sustainable scale-up [16]. Thus, the purpose of this qualitative evaluation of the C2TaP demonstration project was to describe strategies that were successful and those that were less successful or ineffective in identifying and recruiting at-risk youth for HIV testing and linkage to prevention services.

C2TaP was implemented by 12 Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) Adolescent Medicine Trial Units (referred hereafter as sites) and was funded by the Eunice Kennedy Shriver National Institute for Child Health and Human Development and the National Institute on Minority Health and Health Disparities. Implementation activities were conducted between June 1, 2015, and February 29, 2016.

The primary goal of C2TaP was to link HIV-negative youth aged 13–24 years to prevention services. Sites were asked to emphasize testing and prevention services for African-American and Latino young men who have sex with men (subsequently identified as YMSM of color) since these populations are disproportionately represented among new HIV infections [13]. Each site developed and implemented a site-specific HIV testing strategy that used local epidemiological data and built upon ongoing C2P collaborations with local community partners [14,15,17]. Prevention services were broadly defined to include providing access to PrEP, periodic rescreening or testing following high-risk exposures, STI screening, behavioral risk-reduction counseling, referral to online resources, and linkage to other community-based prevention and support services that address mental health, substance abuse, housing, and food security. Linkage to prevention and support services was provided by linkage coordinators who were specifically trained to work with youth and marginalized populations. Newly identified youth living with HIV across all sites were linked to HIV care: overall, 1,172/1,679 (69.8 %) youth were linked to care, of whom 1,043/1,172 (89 %) were engaged in care [18].

Evaluation data and analyses

Informants. Informants were identified collaboratively by C2TaP staff and staff of the ATN's National Coordinating Center (the C2TaP coordination and oversight center). Informants included three individuals from each site, including HIV testing staff, navigators, nurses, project directors, and site principal investigators). The participant sample intentionally focused on site staff members to gain the perspectives of those who planned and implemented the pilot demonstration project. Although study resources did not allow for the direct interviewing of youth recipients of services, their perspectives were gathered at individual sites during the planning and development of projects to ensure a youth-informed design. Also, the youth's perspective was captured indirectly via the staff that was interviewed (see Table 1 for description of informants).

Data collection tools. Interview guides were informed by aims of the demonstration project, the National HIV/AIDS Strategy, and

Table 1
Informants' staff roles

Staff role	n
Project coordinator	9
Project director/supervisor	7
Recruiter/outreach worker	4
Administrator: medical director/ad hoc chair	3
Nurse/nurse manager	3
Principal investigator	3
HIV/STI tester	2
Patient navigator/linkage to care staff	2
Research/training coordinator	2
C2Tap Staff, NOS	1
Clinical social worker	1
Health educator	1
Outreach director	1
Partner notification staff (D.C.)	1
Total participant, N	40

D.C. = District of Columbia; NOS = not otherwise specified; STI = sexually transmitted infection.

the Centers for Disease Control and Prevention recommendations for HIV prevention programs [1,4]. Interview questions were open ended with probes to elicit discussion and to clarify specific aspects of each program. Eighteen core items were administered to all informants, with three to five site-specific items that addressed local conditions and issues. Interview guides addressed six general topics: implementation processes, outcomes, community conditions/infrastructure that impacted program implementation and outcomes, project acceptability, sustainability/scale-up, and lessons learned (see Table 2 for more detailed information on site-specific intervention models and primary outcome measures).

Data collection procedures. Contact information for each informant was provided to the evaluation team by National Coordinating Center staff, and the evaluation team made direct contact to schedule and conduct one-on-one qualitative telephone interviews, with completed interviews audio recorded for transcription. For this evaluation, 40 of 42 potential informants (95%) were interviewed from January to March 2016.

Data management and analyses. Audio files were transcribed verbatim and verified before analyses. Transcriptions were analyzed via Microsoft Excel and Word software, using three cycles of analyses that included descriptive coding, identification of thematic patterns, and conceptual model building. Codes were modeled after the key topics in the interview guide, as well as emergent codes identified during transcript review and preliminary analyses; three evaluation analysts agreed upon all codes. Descriptive codes summarized and categorized passages of qualitative data in short statements. This type of coding led to a categorized inventory of the interview data's content and set the groundwork for thematic analysis. Commonly occurring statements were organized into thematic patterns that accounted for circumstances that supported and challenged linkage to prevention services. Analysts coreviewed a portion of descriptively coded data; discrepancies and queries were discussed among the team until consensus was achieved. Analysts also reviewed and critiqued preliminary thematic findings. Together these processes ensured comprehensive and accurate reporting of findings. Following thematic pattern coding, analysts developed conceptual models by linking themes and emergent codes generated from the first two

cycles of analysis to create higher-level understanding about the relatedness of the different components of an HIV Prevention Continuum for youth and how such a continuum can be best constructed to meet youth's needs. Each participating site's university institutional review board approved the study procedures.

Results

Eight themes were summarized to provide perspectives on testing and linkage to prevention services: (1) relationships with community partners, (2) trust between providers and youth, (3) youth capacity to navigate prevention services, (4) PrEP-specific issues, (5) privacy issues, (6) gaps in health records that prevented tailoring of services, (7) confidentiality of care for youth accessing services through parents'/caretakers insurance, and (8) the need for health-care institutions to keep pace with models that prioritize HIV prevention among at-risk youth. These themes are discussed in the context of factors that facilitated or challenged linkage to prevention services. Illustrative quotes are numbered and detailed in Table 3 to facilitate matching to themes.

Relationships with community partners

Informants noted that although testing often takes place in health-care settings, community partners have indispensable roles in linking youth to prevention services including services for biomedical interventions such as PrEP. Community partners, such as barber shops, recreation centers, and school-based health centers, were characterized as having historical, first-hand relationships with the target population, in-depth understanding of the issues that confront youth, a track record of culturally competent service delivery, and connections within the community that address the particular needs of the targeted youth in a way that most clinical care providers likely do not have (Quotes 1–3).

Youth's trust for providers

Mistrust of health-care systems emerged as a critical barrier to linkage to prevention services. Informants noted that many youth mistrust the commitment of providers to youth's best interests, noting youth of color and gay youth have felt, and still feel, invisible and disenfranchised by providers and health-care systems. This mistrust was especially evident during initial efforts at engagement, and could take several months before youth felt sufficiently secure to reveal levels of risk and commit to prevention services (Quotes 4 and 5).

Addressing youth mistrust required investment of time and effort through building relationships with community partners, direct youth involvement in the design of prevention services, mirroring of community diversity in program staff, and intentional youth-friendly structures for patient engagement and communication. For example, sites supported youth engagement in prevention services by assessing and utilizing preferred communication methods, such as text messaging and mobile phone applications (apps), to maintain contact between appointments (Quote 5).

Barriers to youth navigation of prevention systems

The capacity of young people to address the fragmentation and complexity of prevention services was repeatedly mentioned by informants. Youth-specific barriers that impeded linkage to

Table 2
Site description and primary outcomes

Site	Intervention type	Brief description	Primary measures/outcomes
Chicago	Targeted testing	Social network intervention to recruit, educate, and test high-risk youth. Those who test negative are referred to ELINCC (local Continuum of Care model for HIV-negative youth). Those who test positive are referred to SMILE. Use fourth-generation HIV testing.	Goal = Administer 100 HIV tests for high-risk minority youth ages 13–24 with at least 40 YMSMs less than 18 years of age. Link 100% who test positive to SMILE LTC coordinator Link 80% of negatives to prevention care coordinator
Tampa Bay	Targeted testing	Social network intervention to recruit, educate, and test high-risk youth (offering testing in barber shops/hair salons in high-prevalence zip codes) and enhance data management at youth clinic to standardize risk assessment, linkage to preventive services, PrEP follow-up.	Goal = 200 HIV tests; expect 116 positives identified and linked to care through ATN, STI positives identified and successfully treated, HIV-negative high-risk youth linked to prevention services, youth referred (by self or otherwise) for PrEP services.
Miami	Targeted testing	Expand HIV testing of young MSMs through ACTS (clinic based at UM) by targeting the Alliance (LGBT CBO). Those who test HIV positive will be referred to SMILE, and those who test negative will be referred to the Alliance for psychosocial support.	Goal = 500 tests by ACTS, among MSM (25% minors) and potentially identify at least 6 new positives for LTC through SMILE. 100% will receive routinized one-one prevention services and free condoms through ACTS.
Philadelphia	Targeted testing	HIV testing in two city-funded recreation centers in high prevalence areas that currently lack testing; HIV testing at one alternative high school (E3 Center) using rapid results tests. Those who test negative are referred to preventive and those who test positive are referred for medical services.	Goal = 300 HIV tests. 200 at rec centers; 100 at alternative high school.
Memphis	Targeted testing	HIV testing and linkage services targeting the underground African-American MSM and transgender subculture through pageants, balls, and Greek societies. Those who test HIV positive are referred to SMILE and those who are HIV negative are referred to PrEP provider.	Goal = 100–350 HIV tests, simultaneous STI testing.
Houston	Targeted testing	HIV testing of youth at local Youth Center with LGBTQ program and services. Resources will facilitate HIV testing at community -based venues. SMILE staff will link positives into care and negatives into prevention services such as HATCH, PREP (at Thomas Street Clinic), PEP, counseling, and other services as needed.	Goal = 250 HIV tests; SMILE coordinator facilitates linkage to services. Expect to identify two to four infected youths Target 40 high-risk youths to receive focused follow-up (three contacts) for 8 weeks, will offer prevention counseling and referral to prevention services, encourage repeat testing
Detroit	Targeted testing	Expansion of HIV rapid testing (fourth generation) through three medical venues: Children's Hospital ER, Horizons Clinic, DOH STI Clinic (operated by Wayne State). All testing followed by offering PEP and PrEP. Heavy focus on training staff at three venues to conduct PrEP and PEP referrals and to continue offering HIV testing.	Goal = 100 HIV tests at targeted facilities, including 10 partners/friends of HIV-positive youth; 45 youth at Children's Hospital ER; 40 youth at STI clinic (add in five tests to meet 100).
Boston	Targeted testing	HIV testing and linkage to care and/or preventive services for the most high-risk young black and Latino/Latina and trans[a] MSM via outreach in the Boston Ball Community, at summer youth programs and events, and via van-based testing in the less reached neighborhoods of Boston. HIV positive will be linked to SMILE; HIV negative will be linked to further STI testing or medical care, PEP, PrEP, and mental health and/or substance abuse services.	Goal = 150–200 youths tested (of which 1% will test positive). Of negatives, 100 connected to repeat testing (every 2 months) and 50 linked to services.
Bronx	Routine testing	Routinize HIV testing in four school-based health centers (high schools); increase competency of staff to offer testing and work with LGBT youth.	Increase HIV testing at each of the four health clinics by 10% (from 24% currently to 34%). Ten percent of males accessing HIV testing are engaged in ongoing testing. Three percent of males accessing HIV testing will receive PrEP services. Ten percent of males accessing HIV testing are referred to the Umbrella Program.
New Orleans	Routine testing	Qualitative data collection and outreach focused on youth perspectives; use of web-based screener to promote testing and to identify high-risk youth (assist providers), street and social media outreach, and cataloguing of local prevention resources.	A total of 2,000 youths contacted through outreach/social media; 1,100 screener completions; 300 youths eligible to receive targeted incentives; 140 targeted youths will get HIV test with partner agency; 20 youths referred for HIV LTC; youth HIV/STI testing will increase 10% above 2014 for the same interval; the number of newly diagnosed HIV-positive youth will increase 20% above 2014; prevention website page will be viewed 200 times in 6 months.

Table 2
Continued

Site	Intervention type	Brief description	Primary measures/outcomes
Baltimore	Routine testing	Implement universal HIV testing protocol in the pediatric emergency department to identify HIV-positive adolescents and young adults, including YBMSM, and link them to care services. Identify community partners who offer preventive services (e.g., PrEP) to high-risk YBMSM who test negative for HIV.	Increase the number of 13- to 24-y-olds tested to 50% or 3,144 (compared to 20% in 2014) and identify six YBMSMs, assuming similar positivity rates as 2014.
Denver	Navigation model	Part-time staff member will serve as a PrEP client navigator. Navigator will assist client with navigating financial barriers to accessing PrEP or other prevention services; educating about medication adherence; assist with RIC; assist with referrals for substance abuse or mental health treatment; link client to medical provider at clinic who will be able to order fourth-generation HIV antibody/antigen test and to initiate the complete evaluation for PrEP and prevention services.	HIV testing PrEP referrals, PrEP retention in care Referrals for other preventative care services
Los Angeles	Navigation model	Venue-based navigation and support services designed to support high-risk HIV-negative young gay and bisexual men of color's sexual health and wellness (e.g., PrEP, nPEP, STI screening, HIV testing, primary medical care, and primary and secondary HIV prevention services). Venues = tea parties and pop-up events.	200 YGBMs of color ages 13–24 receive a personalized sexual health assessment conducted by Prevention Navigator, 160 home HIV test kits administered (supervised), 100 youths linked to referral by Prevention Navigator.
Washington, DC	Partner notification	Targeted testing of highest-risk youth (i.e., within detention and residential facilities, foster care and alternative education programs). Supplement the adult partner notification program (currently run through the STI Surveillance Branch of DOH) by embedding a youth coordinator (similar to SMILE program structure) for immediate linkage support/navigation for prevention services.	Goal = 500 tests of youth at risk of HIV infection. At least 80% of these will be YMSM and 90% will be minority youth (Hispanic Latino or black African-American). Anticipate a seropositivity rate of 3%–5% (15–25 new cases). Expect 25 partner notifications with 80% linked to prevention.

ACTS = Adolescent Counseling and Testing Services (based out of Miami); ATN = Adolescent Trials for HIV/AIDS Prevention Interventions; CBO = community based organization; DOH = Department of Health; ELINCC = Early Linkage Intervention for a Negative Continuum of Care; ER = emergency room; HATCH = name of project based at site; LGBT = lesbian, gay, bisexual, and transgender; LGBTQ = lesbian, gay, bisexual, transgender, and queer; LTC = Linkage to Care; MSM = men who have sex with men; nPEP = non occupational post exposure prophylaxis; PEP = post exposure prophylaxis; PrEP = pre-exposure prophylaxis; RIC = Retention in Care; SMILE = Strategic Multisite Initiative for the Identification, Linkage and Engagement; YBMSM = young black men who have sex with men; YMSM = young men who have sex with men.

[a] The term "trans" was used by the Boston project site to be inclusive of individuals who identify as transgender or gender non-conforming.

prevention services included inexperience with navigating healthcare systems and insurance, loss of motivation to engage and remain in health care, transportation barriers, and less well-developed planning and abstract thinking skills that are necessary to remain engaged in health care (Quote 6).

Arranging prevention services was complicated by the array of services needed (e.g., health insurance, mental health, substance use treatment, housing, transportation, and PrEP), in the absence of a single source of comprehensive prevention services. Engagement with youth required patience, development of each client's individual assets, engagement with the client's support system, and persistence. More importantly, youth had little experience with navigating the complexities of healthcare systems and insurance, lacked understanding and skills to manage these complexities, and often had limited family support in addressing these issues. From the perspective of service delivery, the staff skills and time needed to guide youth through these issues was greatly underestimated (Quote 7).

Informants also recognized that youth were developing decision-making and problem-solving skills but needed substantial guidance and support. Less mature youth had less commitment to prevention services and more concerns about revealing their own sexual behavior and risk status to others. These youth were even more likely to need additional support (Quotes 8–10).

Youth were inexperienced with the complexities of arranging prevention services and therefore ill-equipped to do so. They required direct patient navigation approaches and rapid linkage to services. Sites that use navigation services developed scripts for communications with health insurance providers, communicated with insurance companies together with youth, accompanied youth to prevention care appointments, and employed motivational strategies to maintain youth's interest in PrEP and other prevention services. Without this level of support, informants indicated that the process of accessing and maintaining participation in prevention services frustrated and overwhelmed youth, leading to abandonment of the process (Quote 11).

Informants described a range of strategies to reduce structural barriers to linkage and retention in prevention services. A model of more frequent appointments than recommended in clinical guidelines was adopted because shorter interappointment intervals were related to more frequent visits and better adherence to PrEP and other medications. Open, same-day appointments on days following community-based testing events, transportation to appointments, and accompanying youth to appointments were strategies used to ensure linkage to prevention services (Quote 12).

Access to transportation was repeatedly identified as a necessary element of appointment adherence. Mixed responses to public transportation as a barrier-breaking strategy were noted:

Table 3
Representative quotes from program interviewees

Theme	Quote	Attribution
Relationships with community partners	1. The community person, I think there should be a community person because I think without the community piece, we wouldn't have been able to go out to these different venues or these different places to recruit these kids. We have to have relationships.	Chicago
	2. Having partners with deep expertise (in serving HIV/YMSM clients) made a difference in the project. Some community based organizations don't necessarily have the stigma as opposed to you know a "clinic" or hospital setting.	Washington, DC
	3. The borders where we provide services are switching and changing and so our partnerships have to, we have to collaborate with more agencies in order to tackle these issues, the epidemic.	Los Angeles
Youth trust for providers	4. I think what we're saying is we want everybody with HIV to take a pill and we also want everybody without HIV to take a pill as well. So that people are very nervous about that. It sounds fishy… in prior decades, people of color have been targeted and actually been guinea pigs for the medical practices and so people haven't forgotten that.	Denver
	5. With sustained engagement with someone after testing (in terms of just conversations or programs), the person who tests positive usually will get to a level where OK now I'm ready to talk about you know my sex partners and this is the information. But if we launch right to that after test results, they freak out. They are overwhelmed. They disappear. So I'm seeing that that engagement over time has worked a lot better than just you know right after giving them a result going directly into partner notification and trying to elicit their partners like that.	Washington, DC
Barriers to youth negotiation of prevention systems	6. It was really teaching people how they access health care…they were calling insurance for the first time ever. I write up most of the questions to give them to ask. I learned that I'm just not able to say call your health-care company and let me know if they pay for specialty services in network or out of network, … I think the great part was we were able to teach basic health care and how to navigate insurance companies, but we learned that we need to spend a lot more time doing that than we thought.	Denver
	7. We're actually hitting the really high-risk population. We've got a lot of homelessness; we have a lot of commercial sex work…So they are a very high-risk group so we realized that it wasn't, it was something that a social worker level person or medical case manager person couldn't handle alone. We needed to have nursing skills involved… It became a bigger job.	Denver
	8. We need to make it easier for them. You know, systems that we build for adults are not adolescent friendly. And systems that adults are having difficulty navigating, are difficult for kids to navigate. We can't expect kids to navigate systems adults can't.	Houston
	9. I think that linkage things that you do for adults, you can't do with kids and we don't have good procedures for dealing with youth in place yet. We haven't figured it out.	New Orleans
	10. So we did things like try to eliminate extra steps or combining steps together, trying to be responsive to youth culture. We would do reminder phone calls or texting. I combine steps. For example PrEP education and financial obligations together, we did that. … Some insurance required a lot of steps. We weren't able to circumvent all of them.	Denver
	11. You can easily overwhelm a young person coming in with all the forms and the faxing and we have to do this, that and the other. It just becomes very overwhelming. I'm hopeful that having the navigator and having folks that can smooth that process and make it less scary for young people is really helpful.	Denver
	12. Whenever we do testing events, or if we're doing testing out in the field…if we think we're going to have a high volume of tests going on, we usually keep one or two appointments available to make sure that they are there for walk-ins the next day and we can just give the kid a card and say just come in this day and we usually have a call schedule so that case managers, if they are doing things after hours, we have a case manager on call if we need to link to personal care and they need to, we think it would be best if they spoke directly to a case manager and made the appointment and have the explanation linked that way.	Philadelphia
	13. I can't believe that people tell me I have 90 patients scheduled to come to my clinic this week and only 50 showed up. Why didn't those other 40 come? Half the time 20 of them didn't have transportation. Then you send a car to pick up the patient and go back. The cost of that ride, roundtrip, is worth way more than a person not coming to their appointments; having a high viral load and spreading their disease to somebody else.	Miami
	14. The first pop up shop we realized that the area that we were in, it was pretty difficult for the population that we wanted to reach and so it was a flop and we then had to figure out what do we do for the next party and it was really just finding the location that was closer to either public transportation or in the community that held the community members that we were really looking to reach.	Los Angeles
PrEP-specific issues	15. A provider can write a prescription for someone who is under the age of 18, but that would be an off-label prescription and not many providers are willing to do that or want to do that.	Chicago
Privacy and confidentiality	16. We were not able to access all that data from some agencies without written consent and some people were saying it would be easier if we could follow up with participants…We are doing it with some people, but we're not getting all of the information that we want back…	Chicago
	17. When I think about the physicians, they may think they were promoting sex, you know what I'm trying to say. That being the barrier for the physicians, some tell patients, you're too young to be having sex. So maybe those may be barriers. Providers who aren't open to arming kids with the information they need.	Chicago
	18. … this idea of like I don't want the staff to test for HIV because I think he's gay. Again, we don't ask in triage who their sexual partner is, what their sexual orientation is; like any of that information. So, they (i.e., ED staff) wouldn't know that they (i.e., youth) were YMSM or MSM at all, this is a 16 year old black male or female, white female, and so the importance to even say this is something we ask every person between 13 and 21 here…	Baltimore
	19. The most significant barrier (to YMSM of color accessing PrEP) is youth that are on their parents insurance. They technically have coverage, [but] we can't ensure that explanation of benefits after a visit won't get sent to their parents and it would have diagnosis codes going on it. So then they don't qualify for Medicaid; they won't quality for the Gilead patient assistance program.	Denver

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Table 3
Continued

Theme	Quote	Attribution
Changing models of health-care delivery to address high-risk negatives	20. That was something that we hadn't quite anticipated thinking through [when starting a prevention clinic], how are we going to capture this data. It led to another whole new classification of patients that we hadn't ever really had to count before.	Denver
	21. I have the idea, although not any evidence that we may, one way to frame HIV testing now a days is say "well if you're negative, if you're positive, there is something important to do for you to protect you, to give you a long healthy life and protect you but if you're negative there is also treatment that we have to offer you that will also protect you."	Detroit
	22. We've been trying to advocate for getting each of these screening questions to be hard stop which means you can't move forward until you put in a response. If a person says no then you need to put in why the person said no. Maybe they know their status is positive already, maybe they were tested last week. Who knows, but without a place to put that data we just don't know.	Baltimore
	23. We had done a lot of education with like very, very young adolescents, so pre-adolescents and that was unexpected; they certainly required the education; they are very eager to learn and they are evolving in sexual activities. It seems that the youth in here are engaging in sexual activity very early on; as early as 11, 12; so we have done a lot of education.	Philadelphia
	24. In planning with the older young men they do pretty good, … they've actually done very well. They come in motivated, they come in just for that reason; they want it (i.e., PrEP); … . But the younger cohorts, … once you get them started because they just can't seem to keep it together. They're young.	Denver
	25. Access to quality and confidential services; you can make an argument that those services are there and on the flip-side you can make the argument that when communities are so small, that the promise of confidentiality doesn't always feel like it would be upheld… thinking about the LGB community, it can be small and I think there have been concerns raised by community members that you know it's challenging to be tested by a friend or a friend of a friend or things like that. So I think you know there is quality in confidential care; stigma is huge.	Philadelphia

some participants stressed locating services near public transportation to increase access, whereas others noted public transportation as unsafe for youth who present as lesbian, gay, bisexual, and transgender. Providing car service to appointments was thought to be more cost effective than lost prevention opportunities because of missed appointments (Quotes 13 and 14).

PrEP-specific issues

PrEP as a prevention service (rather than simply a prescription medication) highlighted the intersection of legal, financial, and developmental challenges for provision of prevention services to at-risk youth. The medication used for PrEP (a combination of tenofovir disoproxil fumarate and emtricitabine) has not received a Food and Drug Administration indication for PrEP in youth under 18 years of age [19]. Informants discussed "off-label" prescribing in terms of local standards and institutional support for such practices (Quote 15). For youth identified as candidates for PrEP, readiness for a PrEP regimen was lower than expected, requiring much more intensive education and support than what was planned. PrEP medication costs are themselves prohibitive especially since youth under 18 years of age are ineligible for assistance plans from pharmaceutical manufacturers.

Privacy and confidentiality

Client privacy and confidentiality were critical issues in provision of comprehensive provision of services, especially when needed services crossed multiple provider systems. Restrictions on access to protected health information, for example, complicated the process of monitoring youth engagement in various prevention services. Monitoring was particularly difficult when youth were referred to external institutions or when data sharing agreements between providers were not in place (Quote 16).

Tracking engagement in prevention services and health care was further complicated for transient youth because of marginalizing conditions such as homelessness or involvement in human trafficking. Geographical conditions also hindered monitoring efforts, particularly in areas where it was common for youth to cross state lines and jurisdictional borders or areas that serve as entry points to the U.S. Ancillary services such as partner notification were difficult to manage across state/jurisdictional lines. These barriers obfuscated understanding of youth's use of prevention services, meaning that lapses in prevention or emergence of new issues were unaddressed.

An additional barrier to linkage to prevention services had to do with youth's concerns about confidentiality and perceived stigma associated with engaging in these services. Informants noted stigma for both sexual orientation and HIV positivity at multiple levels, including among providers, peers, family members, and youth who internalized stigma. Some providers openly expressed negative judgment about sexually active youth or were uncomfortable asking about youth's sexuality and sexual activity (Quote 17). Youth also reported hesitancy to access services at certain locations for the fear of being perceived as being HIV positive by peers. Thus, youth input into the location of services—within their own community or elsewhere—was critical for successful delivery of prevention services (Quote 18).

Confidentiality relative to parents was also a major concern. Youth desired full control of information that could reveal sexual identity or behavior, including HIV/STI testing, treatment, and PrEP receipt. Informants noted that youth would refuse prevention services rather than risk disclosure to parents. Although prevention services might be covered by parents' health insurance, many youth declined such services because parents would receive an explanation of benefits or equivalent documentation. However, the existing coverage made youth ineligible for public health insurance such as Medicaid. Strategies such as sending insurance explanation of benefits and billing forms directly to youth or the clinic were identified as expedient solutions. Because these

solutions were not institutional or practice policy, they could not be consistently implemented across sites (Quote 19).

Changing models of health-care delivery to address high-risk negatives

Informants noted that the emphasis (e.g., in the National HIVAIDS Strategy, Centers for Disease Control and Prevention High Impact HIV Prevention Strategies) on identifying at-risk HIV-negative youth and preventing incident infection creates the need for a new patient class. Clinical sites have classifications for treatment of clients who test positive for HIV, but have no analogous patient class or clinical infrastructure for high-risk HIV-negative youth. Lack of appropriate risk classification meant that youth could not be linked to prevention services even if HIV testing occurred (Quotes 20 and 21).

A further barrier to linkage to prevention services and health care was incomplete client information collected through electronic health records (EHRs). Although health systems data derived from EHR facilitate tracking of the number and disposition of youth receiving prevention services, most systems are not designed to allow more nuanced population health insights that could support community-level prevention services. One challenge noted was the lack of screening prompts embedded in EHRs. Without such structural support, systematic routine assessments of HIV-related risk factors were often omitted by providers (Quote 22).Underdeveloped capacity to track at-risk youth in terms of geographical area or social networks limited the ability to find key populations of at-risk youth.

Similarly, inability to distinguish levels of risk in HIV testing programs so that services were less effectively tailored to specific youths' needs (e.g., at-risk HIV-negative youth compared with youth without sexual experience). This deficiency challenges local capacity to invest resources in the locations and strategies most successful at reaching at-risk youth (Quotes 23 and 24). Tailoring EHR to collect adequate data also reflects the difficult tension regarding the type of data collected for each client (e.g., sexual orientation and detailed sexual behavior) versus avoiding stigmatization (Quote 25).

Discussion

We evaluated issues related to implementation of testing and linkage to prevention services for at-risk HIV-negative youth in 12 cities across the U.S. Programs were specifically designed to focus on youth with the greatest HIV risk: young sexual minority men (particularly sexual minority men of color). The data point to community, health-care system, and youth-specific issues that challenge HIV prevention programs. Community issues include the substantial service fragmentation as biomedical prevention services become more widely available and potentially take precedence over other prevention modalities. Health-care system issues include ingrained distrust of systems by marginalized populations, lack of efficient information systems capable of supporting continuous prevention services, and lack of capacity to support developmental issues of relevance to youth. Youth-specific issues include the complex intersections of developing sexual identity and the stigma of services that appear identical to those associated with HIV treatment. These issues stand as critical elements that are needed to fully implement an HIV Prevention Continuum to most fully benefit the substantial gains in capacity for prevention, including PrEP.

From these data, we identify five core implementation lessons that could support youth-friendly testing and prevention services. First, engaged community partners are indispensable for successful prevention services. Such partners can bridge gaps between youth and services, empower youth to engage in prevention activities, reduce stigma associated with prevention services, provide connections to community support outside of a given prevention program, and normalize prevention as a standard for behavior [20]. Second, prevention services for youth require greater investment in personnel to guide youth through the complexities of insurance, prior authorization, privacy, and confidentiality [21]. These types of services require substantial personnel time that is often uncompensated and prone to variable success. This means that youth may receive little support for addressing these issues because of lack of personnel, and unequal access to services because of arbitrary or variably interpreted regulations and policies. Third, youth-focused cultural competence training must be cognizant of the intersections of multiple minority statuses—age, race/ethnicity, class, sexual identity, gender identity—that ground HIV prevention as a source of health inequities similar to the health inequities associated with HIV infection. Fourth, effective HIV prevention services need to incorporate information from EHRs to identify ongoing prevention needs and to support developmentally appropriate transitions. Finally, the legal barriers to access to prevention services have to be addressed. Minor consent for HIV prevention services differs from that extended for HIV treatment and is not clearly addressed in most states' exceptions to parental consent for medical conditions such as substance use or STI [22].

Limitations to this research should be considered in forming inferences from these data. First, the research reflects a demonstration project to examine the utility of community-based comprehensive HIV prevention services across sites already participating in a research network. Thus, implementation for testing and linkage to prevention services is built on substantial existing community relationships and experience with working with high-risk youth. Communities with less well-defined experience with HIV in youth could face different issues in the implementation of comprehensive HIV prevention services. Second, the perspectives presented here are from staff from agencies and organizations involved in project implementation. Youth, parent, and community stakeholder perspectives are incorporated into each site's plan for testing and linkage to prevention services. However, data from these key persons were not collected. Finally, PrEP is not approved for use in persons under 18 years of age; perspectives on its implementation may change when this approval occurs.

In conclusion, data from our C2TaP demonstration project provide guidance for implementation of community-based, comprehensive HIV prevention services for at-risk youth. Specifically, we have detailed factors that facilitated or challenged effective linkage to prevention services for at-risk youth. These data provide data to support future design, implementation, and evaluation of fully scaled trials to assess long-term outcomes of comprehensive testing and prevention infrastructures, especially as new prevention strategies become available for dissemination to at-risk youth.

Acknowledgments

Funding Sources

Appendix

C2TaP Interview Guide

Project Processes and Outcomes Now that we've briefly reviewed your pilot project plans, I'd like to take some time to discuss what it was like to implement this project in your city and also what some of the outcomes of this project have been so far.

(1) Reflecting on implementing this pilot project in your community:
   a. To what extent was your project implemented as planned?
   b. What modifications, if any, were made to the original plan? Why?
   c. What worked well?
   d. What could be done to make it work better? Probes
   a. Engaging youth in testing and/or services
   b. Testing process
   c. Linkage to prevention services/care
   d. Retention in care
   e. Other key program components specific to individual sites
(2) What were the outcomes or achievements of this pilot project with regard to the number of youth:
   a. Engaged in HIV testing?
   b. Linked to PrEP service?
   c. Linked to other prevention services? Retained in services?
   d. Were there any unplanned or unintended outcomes (positive or negative)? What were they?

According to project documents and our discussion so far today, successful achievement of planned outcomes for this project would mean <FILL IN SITE SPECIFIC EXS FROM DOC REVIEW OR GLEANED THROUGH INTERVIEW>

(3) Which components of this pilot project do you feel are essential to its success?

Community Conditions/Infrastructure that Impact Project Outcomes When we talk about the success of this pilot project from the perspective of the funder, we're referring to reaching or even exceeding the proposed number of youth that have been tested, linked to appropriate health care and prevention services, and ultimately retained in services and care.

For those who test HIV positive this may include things like medical care, medication adherence programs, and sexual or drug use risk reduction behavioral interventions or other support services. For those who test HIV negative this may include things like risk awareness education, PrEP (pre-exposure prophylaxis) services, ongoing, regular HIV testing and other support services.

(4) Thinking broadly, even beyond the scope of this project, what conditions in your community have contributed to elevated rates of HIV for YMSM of color?
   a. Ex if participant is stuck: unequal access to/quality of services, stigma, oversaturation of prevention messages/services
   b. How does your project address these conditions?
(5) What infrastructure is necessary to enhance or increase HIV testing and linkage to prevention services in your community?
   a. What types of services and programs are already available for HIV positive youth? High risk HIV negative youth? To what extent are they duplicative with or unique from *the <SITE-SPECIFIC NAME> site's HIV Testing and Linkage to Services Pilot Project.*
(6) What conditions or events in the community **contributed** to the success of this pilot project?
(7) What conditions or events in the community **inhibited** the success of this pilot project?

Potential Examples if Participant Requires Prompting:

• Relationships among stakeholders in project
• Contextual barriers: transportation, unstable housing, gang territory lines
• Stigma/stigmatizing events related to YMSM of color
• Current federal/local funding levels for testing/services/care
• Oversaturation/competition with other HIV healthcare and prevention services

Pilot Project Acceptability & Benefit In addition, we'd like to know more about how this pilot project planned for the cultural acceptability of this project among young men of color who have sex with men (YMSM of color) as well as the cultural competence of staff implementing the project. When we talk about cultural acceptability we're referring to the extent to which YMSM of color positively

received and took part in/adopted project interventions. When we talk about cultural competence we're referring to the capacity of project staff to effectively interact with people from different cultures and backgrounds, in this case, YMSM of color.

(8) What steps, if any, were taken to ensure the cultural acceptability among YMSM of color for this pilot project?

(9) What steps, if any, were taken to ensure the cultural competence of staff implementing the pilot project in working with YMSM of color?

(10) What would you do differently in the future to enhance the cultural acceptability among YMSM of color for this pilot project?

(11) *(If not done already)* Can you please provide an example of culturally competent care for your project and how it made a difference in engaging youth?

(12) To what extent does the pilot project use a patient-centered approach?
   a. *(If not done already)* Can you please provide an example of a patient centered approach your project utilizes and how it made a difference in engaging youth?

<Note: By patient-centered, we mean an approach to care and services in which participants and their loved ones/families are actively involved in the decision-making and care that they receive>

Lessons Learned We'd also like to take some time to reflect back on what you have learned so far from this pilot project that can be shared to enhance future HIV testing and linkage to services interventions for adolescents.

(13) What did you learn from this pilot project that will help inform how best to
   a. Reach this particular group of individuals in the future?
   b. Engage them in testing?
   c. Link this group to services/care?
   d. Retain this group in services/care?

(14) What would you do differently in the future if you were to repeat this pilot project?

Pilot Project Sustainability & Scale I'd also like to hear your thoughts about sustaining this project into the future and potentially scaling it up to reach even more youth (or young people).

(15) What barriers, if any, need to be overcome to sustain this project into the future?
   Probes:
   a. Institutional policies/practices
   b. Stigma

(16) Alternatively, what resources would be required to sustain or continue this project in the future?
Probes:
   a. Funding
   b. Relationships/Partnerships
   c. Staffing
   d. Other

(17) Which components of the work are sustainable <u>without</u> additional funding?

(18) What would be needed to scale-up this pilot project to meet the needs of more young people in your city?

That is the end of the questions that we have for today. Is there anything else you'd like to add that we may have missed today?

Thank you so much for your time and insights about the C2TaP (C2P HIV Testing and Prevention) Project. We couldn't do this work without you.

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