Interdisciplinary HIV Sentinel Case Review: Identifying Practices to Prevent Outbreaks in Philadelphia

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**Introduction**: The Ending the HIV Epidemic in the U.S. initiative considers cluster and outbreak response essential. This article describes the design, implementation, and early findings of a Philadelphia-based project to systematically assess sentinel cases among priority populations for improving public health infrastructure and preventing future outbreaks.

**Methods**: Sentinel HIV cases (i.e., early-stage or acute infection or molecular cluster cases) were identified among priority populations (Black and Hispanic/Latino men who have sex with men, youth aged 18–24 years, and transgender people who have sex with men). Chart abstraction and structured interview data were reviewed to determine themes and service gaps and to identify, prioritize, and implement recommendations. Interdisciplinary review teams included individuals with lived experience, frontline staff, and local agency leadership.

**Results**: Data were collected during July 2019–December 2020 and analyzed for 53 of 126 sentinel cases of HIV diagnosed since July 1, 2018. The majority were men who have sex with men (79.3%), those aged 18–24 years (67.9%), and non-Hispanic Black (67.9%). More than half received sexually transmitted infection and HIV testing ≤3 years preceding HIV diagnosis (56.6% and 54.7%, respectively), had a healthcare visit within 12 months before diagnosis (64.2%), and had no evidence of pre-exposure prophylaxis awareness (58.5%). Project recommendations effectuated actions to improve pre-exposure prophylaxis provision, integrate sexually transmitted infection and HIV testing, and educate primary care providers.

**Conclusions**: HIV sentinel case review is a model for health departments to rapidly respond to recent transmission, identify missed HIV prevention opportunities, strengthen community partnerships, and implement programmatic and policy changes. Such efforts may prevent outbreaks and inform longer-term strategies.

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outbreaks identified that a delayed response reduced the opportunity to substantially prevent transmission.

Alternatively, rapidly deployed actions not only help to control the immediate outbreak but also can prevent future ones or reduce incidence. Directing prevention efforts to groups where active transmission is occurring by detecting clusters or acutely infected individuals and enhancing the systems they interact with may disrupt onward transmission. Using surveillance-based identification of networks to strengthen prevention systems is paramount.

If a rapid response to outbreaks can prevent transmission and if the public health response to address gaps in service delivery can prevent future outbreaks, the authors hypothesize that reviewing sentinel cases might help identify and address existing gaps before an outbreak. Partnerships are crucial to successfully implement these efforts.

An existing model for multisectoral stakeholder collaboration is Fetal Infant Mortality Review applied to HIV. In these programs, a case review team (CRT) reviews cases of perinatal HIV transmission and high-risk exposures to identify service gaps. A community action team (CAT) executes interventions to mitigate those gaps.

It is critical to ensure that individuals with lived experience are represented in decision making to shape public health policy and offer insight. Stigma, routinely perpetuated by public health and medical systems toward individuals living with or at risk for HIV, and the resulting mistrust persist as barriers to HIV prevention and care engagement, particularly among youth, Black and Hispanic/Latino men who have sex with men (MSM), and transgender individuals.

The Fetal Infant Mortality Review methodology has not been applied to assess sentinel HIV cases and identify and address systemic gaps to prevent outbreaks. In Philadelphia, where an estimated 18,798 people were living with diagnosed HIV as of December 2019, of whom 439 were newly diagnosed in 2019, the Philadelphia Department of Public Health (PDPH) developed a demonstration project that applied such a model. The detection of clusters of related HIV infections among MSM, disproportionately high incidence of new diagnoses among MSM (48.8%) and youth aged 13–24 years (25.6%), and the misclassification of transgender women who have sex with men as MSM in the HIV surveillance system prompted PDPH to focus the project on these populations. This paper presents the design, implementation, and early findings of this project: Demonstrating Expanded Intervventional Surveillance (DExIS).

METHODS

This project identified sentinel HIV cases, determined missed opportunities for prevention, and formulated action steps to mitigate the identified gaps. The first step of the process was selection of eligible cases.

Study Sample

Sentinel cases were identified among 4 populations: Black MSM, Hispanic/Latino MSM, youth aged 18–24 years, and transgender people who have sex with men. Using HIV surveillance data, sentinel cases were diagnosed with HIV in Philadelphia on or after July 1, 2018 and had evidence of Stage 0 infection and were associated with molecular transmission clusters or both. Stage 0 infection (early-stage or acute infection) was determined on the basis of a negative or indeterminate HIV test ≤180 days before a positive result or by the results of a Centers for Disease Control and Prevention–approved testing algorithm that indicated acute HIV infection. Clusters were identified by analyzing HIV molecular sequences using the Centers for Disease Control and Prevention’s Secure HIV TRANsmission Cluster Engine.

A pairwise genetic distance threshold of 1.5% was used to identify closely related infections.

Measures

A 2-phase, mixed-methods data collection protocol, including medical record abstractions (MRAs) and interview of sentinel cases, was designed. The study team had access to identifiers but did not include them in the central database. Domains and measures were chosen on the basis of the potential for actionable public health interventions (Table 1). If information conflicted between sources, interview responses took priority over MRA data.

Sentinel cases were identified in July 2019, February 2020, and August 2020 for diagnoses during July 1, 2018—January 30, 2020. This paper reflects data collected on cases during July 2019—December 2020 and analyzed in 2020.

The MRAs were completed using the enhanced HIV/AIDS Reporting System and the sexually transmitted disease (STD) Control Information Database, PDPH’s sexually transmitted infection (STI) surveillance and Partner Services database. Beginning in mid-2020, MRAs from the facility of HIV diagnosis were conducted if PDPH had remote access to the facility’s electronic medical record. These sources provided information on demographics, STI testing and diagnosis (for syphilis, gonorrhea, and chlamydia), HIV testing and diagnosis, and Partner Services interviews, including any discussion about pre-exposure prophylaxis (PrEP) or nonoccupational postexposure prophylaxis (nPEP) awareness or utilization (Table 1).

A standardized interview, designed to complement MRAs, included quantitative and qualitative components. Outreach was conducted to eligible sentinel cases by telephone calls, text messaging, and mailed letters using contact information from the enhanced HIV/AIDS Reporting System. The interview was voluntary, and participants were compensated. Interviews were conducted by telephone or in private spaces at PDPH; after spring 2020, in response to the coronavirus disease 2019 (COVID-19) pandemic, interviews were offered in an abbreviated telephone format consolidated to remove duplication.

A 3-team structure was designed to review and discuss MRA and interview data. Each team had a specialized role and averaged 15 members. Meetings, initially held in person, were suspended in summer 2020 as staff were redeployed to COVID-19 response and subsequently resumed through a virtual format.
Table 1. DExIS Domains and Measures Obtained Through Data Collection Tools

<table>
<thead>
<tr>
<th>Domains</th>
<th>Chart abstraction</th>
<th>DExIS interview</th>
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<tbody>
<tr>
<td>Demographic</td>
<td>Age, current gender, sex at birth, race, ethnicity, region of residence, transmission group</td>
<td>Sexual orientation, current gender, race, ethnicity, language, region of residence</td>
</tr>
<tr>
<td>Housing and financial</td>
<td>Homelessness</td>
<td>Housing status, work status, sources of financial support, insurance status</td>
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<tr>
<td>Exposure to justice system</td>
<td>Incarceration status</td>
<td>Previous interaction(s) with law enforcement</td>
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<tr>
<td>Social experiences</td>
<td>Number of sexual partners</td>
<td>Social media app use, HIV status disclosure, identity disclosure, social and emotional supports, participation in LGBTQ affinity spaces, anxiety surrounding sexual experiences, acceptance at school and by family and friends</td>
</tr>
<tr>
<td>Religion and spirituality</td>
<td></td>
<td>Importance of religion and spirituality, impact on self-image</td>
</tr>
<tr>
<td>Stigma</td>
<td>Facilities and results of gonorrhea, chlamydia, and syphilis tests before and after HIV diagnosis; facilities of HIV tests before and after HIV diagnosis; PrEP and nPEP awareness, utilization, frequency of use, and reasons for discontinuing or not initiating</td>
<td>Preferred locations for testing; testing anxiety; reasons for testing; provider support after diagnosis; PrEP and nPEP awareness, utilization, frequency of use, and reasons for discontinuing or not initiating; provider discussions surrounding PrEP and nPEP; syringe or needle sharing; conversations with partners; sources of sexual wellness information</td>
</tr>
<tr>
<td>HIV and STI prevention</td>
<td>Facilities and types of providers visited for medical care before and after HIV diagnosis, comorbidities and treatments, CD4 counts and viral loads</td>
<td>Preferred locations for care; comfort with provider discussions of sexual health, HIV, and substance use; experiences of discrimination by medical providers; trust in provider</td>
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<tr>
<td>Primary medical care</td>
<td></td>
<td>Positive and negative experiences seeking mental health services, reasons for not accessing services, experiences seeking substance use treatment, reasons for not seeking substance use treatment</td>
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<tr>
<td>Mental health and substance use</td>
<td>Mental health and substance use treatment utilization</td>
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app, application; DExIS, Demonstrating Expanded Interventional Surveillance; LGBTQ, lesbian gay, bisexual, transgender, and queer; nPEP, nonoccupational postexposure prophylaxis; PrEP, pre-exposure prophylaxis; STI, sexually transmitted infection.

The CRT included staff across PDPH divisions, including personnel with expertise in HIV prevention and treatment, STIs, viral hepatitis, adolescent care, substance use prevention, chronic disease, and injury prevention. Keeping the CRT within PDPH allowed for increased confidentiality. Information from a person’s MRAs and interview, when available, were synthesized into a single deidentified case summary report for team members. At each monthly meeting, the CRT reviewed 4–6 cases and identified the key themes related to service gaps.

The CAT included community members and frontline staff from agencies across Philadelphia with expertise in (1) prevention (i.e., HIV/STI testing, PrEP); (2) treatment (i.e., primary, emergency, and HIV care); (3) behavioral health; (4) HIV prevention research; (5) social and cultural programming (i.e., lesbian, gay, bisexual, transgender, and queer community centers); and (6) legal, regulatory, and policy (i.e., City of Philadelphia agencies and public interest law firms). The CAT did not review individual cases, but at quarterly meetings, they reviewed the key themes identified at CRT meetings and deidentified cumulative, aggregate case data. The CAT proposed systems-focused recommendations for change on the basis of the presented data.

The policy implementation team (PIT), which met quarterly, included leaders working in the 6 areas of expertise represented on the CAT, including PDPH leadership. CAT and PIT membership overlapped so that perspectives of both client-facing and administrative-level staff could inform team discussions. The PIT received the same cumulative, aggregate case data reviewed by the CAT and the CAT’s recommendations. They fine-tuned the recommendations, prioritized them according to anticipated impact versus effort, and created action plans for those determined most feasible.

The PDPH IRB determined that this project was not research. All local, state, and federal protocols regarding the security and confidentiality of HIV data were followed. Data were deidentified before review by any of the 3 DExIS teams. Informed consent was gathered before interviews.

Statistical Analysis

Sentinel cases were described by demographics, HIV and STI testing histories, preferred site for HIV testing, healthcare visits prediagnosis, perception of HIV risk, and PrEP/nPEP awareness and
usage. Cases with and without interviews or abstractions were compared by demographics, HIV diagnosing facility, and previous STI diagnoses. Bivariate analyses were performed using Fisher’s exact tests to evaluate the associations between evidence of a healthcare visit 12 months before HIV diagnosis and evidence of (1) PrEP awareness and (2) PrEP usage. All statistical analyses were completed using SAS, version 9.4. Significance was determined at the $p=0.05$ level. Findings from MRAs and interviews and discussion points by the CAT that resulted in recommendations and action plans by the CAT and PIT are highlighted.

RESULTS

During July 2, 2018—January 30, 2020, a total of 675 cases of HIV were newly diagnosed in Philadelphia; 126 (18.7%) met sentinel case criteria. In total, 83 (12.3% of new diagnoses) cases were Stage 0 diagnoses. As of December 2020, data were collected for 53 cases. In total, 40 cases were Stage 0 (75.5%), 9 (17.0%) were associated with molecular clusters, and 4 (7.5%) met both criteria (Table 2). All the 53 cases had enhanced HIV/AIDS Reporting System and STD Control Information Database abstractions, and 13 had other MRAs. Majority of the cases were MSM (79.3%), aged 18–24 years (67.9%), and non-Hispanic Black (67.9%) (Table 2). A total of 4 (7.5%) individuals identified as transgender. A total of 37 (69.8%) individuals had contact information available and were selected for interview. A total of 12 individuals completed interviews; 11 declined; 2 agreed to participate but were not shown; and 12 were unable to be located, despite multiple attempts. In total, 42 of the 53 cases were reviewed by the CRT by December 2020; the remaining 11 cases were not reviewed by December 2020; the remaining 11 cases were not reviewed by December 2020 owing to COVID-19–related hiatus.

Of the 53 cases, 30 (56.6%) had evidence of $\geq 1$ STI tests $\leq 36$ months before HIV diagnosis. Slightly less than half (45.3%) had $\geq 1$ STI diagnosis in this timeframe (mean positive tests, 2.4; 95% CI=1.7, 3.2) (Table 2). These positive tests could represent multiple diagnoses on the same day, repeat tests for the same diagnosis (if untreated), or represent multiple diagnoses. More than half (54.7%) had $\geq 1$ negative HIV test $\leq 36$ months preceding diagnosis; of these, 7 had a test $\leq 6$ months before diagnosis, 15 had a test 6–36 months before diagnosis, and 7 had a test within both timeframes.

Majority of the 53 cases (64.2%) had evidence of $\geq 1$ visits to a healthcare provider $\leq 12$ months before HIV diagnosis (Table 2). All the 12 interviewees said that they had a primary care provider (PCP). Half reported discussing HIV testing or risk reduction strategies with their PCP in the year before diagnosis. Half reported that in retrospect, their preferred site for HIV testing would be a doctor’s office. Rationales included feeling at ease and supported there and finding their doctor to be lesbian, gay, bisexual, transgender, and queer—friendly.

Interview data also reflected self-reported likelihood of HIV acquisition. Half of the interviewees said that before HIV diagnosis, they thought it was somewhat unlikely or very unlikely that they would acquire HIV, and 2 were neutral.

Among the 53 cases, less than half had evidence of PrEP awareness (41.5%), and less than a quarter had evidence of ever using PrEP (17.0%) on the basis of MRAs or assessed through the interview (Table 2). There was a significant association between evidence of a healthcare visit $\leq 12$ months before HIV diagnosis and evidence of PrEP awareness ($p<0.0001$). Summarized data from the STD Control Information Database, MRAs, and interviews indicated that the reasons for not initiating or for discontinuing PrEP were not feeling that they needed it ($n=4$), concerns about or experiences of side effects ($n=3$), limited knowledge of PrEP ($n=2$), missed appointments ($n=2$), testing positive at a PrEP initiation appointment ($n=2$), concerns about privacy ($n=1$), and provider refusal to prescribe ($n=1$). Two of the 53 cases (3.8%) had evidence of nPEP usage (Table 2).

Key Findings and Recommendations Generated by Review Teams

The review teams proposed several recommendations in response to identified missed opportunities (Table 3). These centered on enhancing components of clinical workflows to make HIV prevention standard of care. Proposed mechanisms included optimizing EMR features; developing standardized protocols for PrEP delivery; routinizing STI and HIV testing; reaching PCPs and emergency departments with training resources; and reaffirming the legal rights of healthcare consumers to quality, compassionate medical care.

Multiple recommendations led to implemented action steps. A PDPH health update was disseminated in February 2020 to medical providers, including PrEP and HIV care providers, to clarify the clinical guidelines for 2 PrEP regimens—tenofovir disoproxil fumarate/emtricitabine and tenofovir alafenamide/emtricitabine—in response to individual narratives indicating concerns about side effects and misinformation influenced by PrEP decision making. Because of the recommendations to better integrate STI and HIV services, PDPH executed 2 action items. An effort to develop low-threshold sexual health services sites was incorporated into Philadelphia’s Ending the HIV Epidemic plan, and a Request for Proposals was released in January 2021. These clinics will
colocate HIV and STI testing and treatment services as well as PrEP and nPEP counseling within single facilities to promote utilization. In addition, resources for medical providers on taking a comprehensive sexual health history and a biosocial HIV screening policy were developed. The policy provides guidance on HIV screening on the basis of a biological risk factor, such as STI diagnosis, or identification with a population with disproportionate HIV prevalence, such as MSM. This was influenced by the fact that 50% of interviewees would
have preferred HIV testing at their PCP; yet, only 50% said that their provider discussed HIV in the year before diagnosis. This policy seeks to expand routine STI and HIV screenings in healthcare settings. In response to low nPEP utilization among sentinel cases, PDPH is establishing a centralized system to support nPEP delivery through a request for proposals to establish nPEP centers of excellence, a clinician-staffed nPEP hotline, and linkages to pharmacies.

**DISCUSSION**

Interdisciplinary sentinel case reviews highlighted missed HIV prevention opportunities within the medical and

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<th>Missed opportunity</th>
<th>Recommendation</th>
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<td>Most individuals had previous STI testing; yet, most had no evidence of PrEP awareness.</td>
<td>Encourage hospital systems to optimize EMR features so that a positive STI diagnosis prompts opt-out HIV testing and a discussion about PrEP. Create in-service training modules for primary care providers and emergency departments that present plausible pathways from an STI test to HIV testing and status-neutral linkage to PrEP or ART. Invite all staff at facilities, including front desk staff, to these trainings to identify new champions. Create draft protocols on various topics (PrEP provision, STI testing, HIV testing) for providers who become interested after in-service trainings through PDPH health alerts or by other means to develop their own standard operating procedures. The draft protocols may make future technical assistance easier. Disseminate a PDPH health advisory to facilities with guidelines for concurrent HIV–STI testing and same-day PrEP initiation. PDPH can provide technical assistance to facilities to help them develop their own protocols.</td>
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<td>nPEP uptake remains very low among people with an indication for it.</td>
<td>Establish a centralized mechanism to scale up nPEP awareness and provision through nPEP centers of excellence, a clinician-staffed nPEP hotline, and linkages to pharmacies.</td>
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<td>Most individuals had an interaction with care in the year preceding HIV diagnosis. Only half of the individuals interviewed said that their primary care provider discussed HIV in the year before diagnosis. Half of the individuals interviewed would have preferred to get HIV testing at their primary care provider. PrEP does not always feel relevant to people who may be able to benefit from its protection. Individuals may feel that they are unlikely to acquire HIV.</td>
<td>Create multiple resources with the 8Ps* of taking a sexual history for providers to use as a component of biopsychosocial screenings. Formats include laminated, pocket guide, paper intake form, tablet survey, and detailed instructions to integrate into the EMR using built-in features. Ensure that educational materials for primary care providers on risk reduction and combination HIV prevention emphasize the importance of avoiding stigmatizing language when interacting with clients. Develop a standardized patient module for providers to simulate conversations surrounding risk reduction with clients, including PrEP counseling.</td>
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<td>Concerns about privacy may influence PrEP initiation or adherence. Providers may be refusing to prescribe PrEP to people who have an indication for it.</td>
<td>Develop a consumer education kit similar to New York City’s LGBTQ Health Care Bill of Rights. Include the right to talk to a provider alone and with privacy. Include a grievance line for individuals that offers a phone number to report dissatisfaction with providers refusing to provide PrEP when indicated or conduct HIV or STI testing when requested.</td>
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<tr>
<td>Concerns about side effects may influence PrEP initiation or adherence.</td>
<td>Issue guidance to providers to schedule a follow-up call or check-in with patients 1–2 weeks after PrEP initiation to discuss side effects and possible management. Disseminate a PDPH health update to providers that addresses targeted misinformation surrounding the efficacy and safety of TDF/FTC and TAF/FTC PrEP regimens and clarifies prescribing guidelines.</td>
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*S The 8Ps are a framework developed by Fenway Health to guide medical providers in taking a sexual health history. They build upon the 5Ps model developed by the Centers for Disease Control and Prevention. The 8Ps include questions on preferences, partners, practices, protection for STIs, past history of STIs, pregnancy, pleasure, and partner violence.

ART, antiretroviral therapy; EMR, electronic medical record; FTC, emtricitabine; LGBTQ, lesbian gay, bisexual, transgender, and queer; nPEP, nonoccupational postexposure prophylaxis; PDPH, Philadelphia Department of Public Health; PrEP, pre-exposure prophylaxis; STI, sexually transmitted infection; TAF, tenofovir alafenamide; TDF, tenofovir disoproxil fumarate.
public health system. These centered upon reinforcing HIV prevention at STI testing and medical visits before HIV diagnosis, addressing concerns about patient privacy and PrEP side effects, expanding PrEP education for providers, and scaling up nPEP prescribing and delivery.

A strength of this approach was leveraging the recommendations jointly developed by individuals with lived experience, client-facing staff, and agency leadership to address frequently cited service gaps. Consistent with previous studies, this analysis shows that individuals with recently acquired HIV infection were engaged in the medical system before diagnosis. A prevailing theme was the need to solidify STI, HIV, and PrEP services within primary care workflows. On the basis of interview questions directly gauging PrEP awareness and the absence of PrEP documentation in medical charts, majority of the cases had no evidence of PrEP awareness, even though the majority did have evidence of STI and HIV testing in the 3 years before HIV diagnosis. Previous research among MSM and transgender individuals associated with HIV transmission networks observed low PrEP uptake. The review teams suggested optimizing EMR features and creating protocols to make STI and HIV testing and PrEP delivery standard of care. The review teams also proposed prioritizing PrEP training for PCPs who commonly diagnose STIs and emphasized inviting nursing staff, medical assistants, and front desk personnel to identify new PrEP champions. The DExIS methodology allowed PDPH to identify and address systemic barriers to HIV prevention.

DExIS presents a model for HDs to reinvigorate relationships with key partners. Before DExIS, no formalized mechanism existed for wider cross-divisional collaboration within PDPH to promote HIV prevention. DExIS allowed for PDPH staff within and outside of the HIV division to engage in structured conversations where all participants reviewed the same information, determined patterns, and conceptualized changes to their own work. Examples included leveraging other divisions’ partnerships with medication-assisted treatment providers and workshops routinely led by PDPH’s youth care team to expand PrEP access. DExIS also helped to establish clear responsibilities of community partners and PDPH in advancing action items. PDPH could develop a work product, such as a health advisory, and solicit feedback from CAT and PIT members to clarify and strengthen messages.

A challenge to implementing DExIS was engaging the highest levels of hospital administration in executing action items. PIT participants were committed to enhancing the HIV prevention landscape and were leaders at their institutions. However, some of the recommendations transcended the purview of any individual provider. For example, enhancing EMRs with prompts to discuss PrEP or HIV testing would require buy-in from hospital administrators to work with their EMR provider to install these features. Prioritizing HIV prevention at the hospital administration level is an ongoing challenge that requires HDs to carefully convey how HIV prevention fits in among their competing needs, particularly as they continue to respond to the COVID-19 pandemic.

**Limitations**

There are limitations to this analysis. The sample size represented only 8% of newly diagnosed individuals. Stage 0 cases (75.5%) represented a higher proportion than those associated with molecular clusters (17%) (Table 2). Molecular cluster identification can be delayed compared with Stage 0 identification. As a result, recommendations may skew toward addressing the needs of individuals acutely infected rather than those associated with clusters. Although the number of interviews completed was small, DExIS teams still reviewed cases without interviews but with MRA information. Outdated contact information limited the success of interview outreach. Moving forward, public records databases and PDPH’s immunization database will be consulted for updated contact information. Because MRAs were restricted to institutions to which staff have EMR access, the collected data are a limited reflection of one’s entire medical care history. Finally, jurisdictions with limited staff may have to adapt the 3-team structure and can consider consolidating the CAT and PIT into 1 team jointly responsible for proposing recommendations and creating action steps.

**CONCLUSIONS**

The DExIS methodology shows promise as a model for HDs to rapidly respond to recent HIV transmission and use that information to implement changes to programs and policies. When a history of previous negative HIV tests is available, an individual’s Stage 0 HIV diagnosis may be sooner determined by HDs than their association with a molecular cluster. By investigating these acute and early-stage diagnoses, systemic gaps can be addressed, which may mitigate the growth of future outbreaks. Jurisdictions may benefit from the ability of DExIS to drive Ending the HIV Epidemic in the U.S strategies, identify gaps across HIV prevention and care systems, and build or strengthen community partnerships. They can also tailor the sentinel case criteria and expand beyond priority populations, depending on their investigation capacity. Moving forward, recently introduced interview questions surrounding the impact of COVID-19 on care-seeking behaviors and individual demonstrations of resiliency will also be analyzed. In addition, sentinel case eligibility will be expanded to review more
cases among people who inject drugs, including MSM who inject drugs, to accelerate the real-time response toward a current outbreak among people who inject drugs in Philadelphia.27

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REFERENCES


