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Furthering Discussion of Ethical Implementation of HIV Cluster Detection and Response

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Molldrem and Smith’s (2020) “Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice,” outlines important considerations toward more ethical use of HIV data collected and used for public health. As both the HIV and coronavirus disease 2019 (COVID-19) pandemics have demonstrated, social justice concerns and historical struggles against inequality and oppression cannot be separated from public health (Bailey et al. 2017). Public health efforts aimed at reducing transmission of infectious disease often succeed in protecting relatively privileged groups, while allowing persons from oppressed groups to experience disproportionate harms (Jeffries and Henny 2019). Documenting these disproportionate harms is necessary, but not sufficient, to address ongoing HIV disparities.

Cluster detection and response (CDR) is a public health approach to focus prevention efforts where increased transmission is occurring. Although the use of molecular CDR efforts in HIV is relatively new, these methods have been used in many other areas of public health. Discussion of CDR often focuses on the collection and use of molecular HIV sequences, but in practice this work encompasses a variety of prevention, early diagnosis and treatment activities, from identifying prevention and care needs for individuals (e.g. contact tracing, testing, and referral to antiretroviral treatment) to addressing gaps in programs and services for communities (e.g. additional funding and redistribution of resources such as pre-exposure prophylaxis (PrEP), testing, or syringe services programs). Molecular analysis allows health departments to more easily detect rapid HIV transmission, signaling gaps in prevention and care services which can then be addressed using traditional HIV prevention tools (Oster et al. 2018).

CDR approaches have directly informed expansion of access to HIV resources among disproportionately affected communities. For instance, Massachusetts identified connections between networks of people who inject drugs in different areas of the state, providing support for successful expansion of syringe service programs (Cranston et al. 2019).

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Investigation of a network of rapid transmission in Texas highlighted missed opportunities for testing and PrEP. Community-level response included expanded PrEP access, increased routine HIV testing in hospitals, and a city-wide partnership providing expanded HIV resources to the community (Taylor 2018). Despite promising early evidence, additional implementation science, prospective studies, and demonstration projects are needed to better understand optimal CDR approaches.

In 2019, CDC's Division of HIV/AIDS Prevention (DHAP) convened a series of conversations (CDC 2020) to discuss this work, part of an ongoing process to consider the ethics of new developments in HIV surveillance data collection and uses (Sweeney et al. 2013). Participants underscored the need to consider the effect of CDR efforts on stigma and disparities, to better understand real-life impact, and to establish program effectiveness. Early evidence suggests that CDR efforts may be most effective when used to identify and address gaps in existing HIV prevention and care systems. Use of these data at a population level can highlight gaps in access to treatment and care, providing compelling support to expand needed services and more equitably distribute resources. Instead of focusing on punitive measures, public health efforts using CDR (or any public health data) are more likely to earn trust and ultimately be successful when supporting people to access needed and desired services. Additional research can help identify the best ways to translate specific CDR findings to the most effective structural and supportive public health interventions for both individuals and communities. Individual interventions such as partner services and linkage to care efforts must be sensitive, non-coercive, and culturally appropriate. Efforts focusing response solely on outreach to persons identified as part of an HIV cluster are likely to miss persons with HIV who have not been tested and in need of care, and such efforts are unlikely to identify structural barriers enabling rapid transmission. CDR activities may be most effective when used to identify and address gaps in existing HIV prevention and care activities as part of a jurisdiction-wide approach.

CDC and health departments also have an ethical responsibility to ensure that methods result in measurable benefits and minimize harm. Mollrem and Smith and others have raised concerns about potential use of molecular HIV data in criminal transmission cases. Stakeholders have recommended collection of information on harms or unanticipated outcomes of CDR. Additional collection of harms associated with HIV public health efforts (e.g. requests for health department data for use in criminal investigations, accidental disclosure of HIV status or other breaches of confidentiality in the course of follow up activities, etc.) would provide important information to programs seeking to reduce harms in the future.

CDC's National HIV Surveillance System does not contain individuals' name or address, and CDC data protections prohibit data release for uses other than public health purposes and release of data is governed by strict data release policies. However, health department data do contain personally identifiable information, and state policies vary widely regarding protection and release of data for nonpublic health purposes. State HIV criminalization statutes are not generally science-based, have not been shown to prevent HIV transmission, and may cause harm by, for instance, increasing stigma and mistrust. Until a national standard for protection of public health data is adopted, uneven state level protections pose

risks for individuals, public health data, and the public's trust (Lee and Gostin 2009). Mollidrem and Smith note scientific debate about the ability to determine directionality of transmission using molecular data. Given the lack of agreement among experts in this field, the risks to individuals, and known gaps in data, we agree about the limitations of these data to infer transmission direction.

Monitoring reportable conditions is an essential public health function; data collection without explicit patient consent is authorized by state laws and founded in public trust and is necessary to ensure accurate understanding of health risks and disparities. CDC and health departments have sought to incorporate ethical analysis and a code of restraint when considering implementation of new uses of surveillance data (Fairchild et al. 2007). Maintaining public trust and increasing transparency of public health monitoring systems are particularly important given declining trust in public institutions (Rainie et al. 2019). Consideration of new mechanisms to increase awareness of public health surveillance and prevention activities, guided by ethics and justice frameworks, could help move public health agencies toward increasing transparency, autonomy, and trust.

Public health agencies have an ethical duty to initiate and expand efforts to engage key communities, to increase public awareness of HIV surveillance in general, and HIV CDR in particular. During DHAP's 2019 discussions, many participants identified a need to go beyond engagement with HIV planning groups, and to make information and engagement accessible to broader communities. Stakeholders stressed that marginalized groups are often at increased risk of HIV and frequently targeted by policing and immigration enforcement, and that public health agencies and staff need to consider this context when developing public health programs and interventions. Increased engagement, collaboration, and conversation between public health agencies and the communities they serve could help address these concerns, minimize distributive justice issues, and strengthen public health work. The optimal methods and mechanisms for community engagement vary, but increased community engagement at all levels is needed. Additional cluster implementation guidance issued by CDC in November 2018 (CDC 2018) underscored the importance of community engagement in this work, as well as requiring funded jurisdictions to assess data protections and local legal context.

In conclusion, Mollidrem and Smith have made an important contribution to the discussion of the ethics of HIV surveillance and CDR. We appreciate their application of HIV data justice framework to the topic of CDR and feel that consideration of this framework may provide opportunities to better incorporate consideration of justice in discussions of HIV surveillance ethics.

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