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COMMENTARY



Predictive analytics in HIV surveillance require new approaches to data ethics, rights, and regulation in public health

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ABSTRACT

In recent years, applications of big data-driven predictive analytics in public health programs have expanded, offering promises of greater efficiency and improved outcomes. This commentary considers the turn toward predictive modeling in US-based HIV public health initiatives. Through two case studies, we analyze emergent ethical problems and risks. We focus on potential harms related to (1) classifying people living with HIV in public health systems, (2) new ways of combining and sharing individuals' health data that predictive approaches employ, and (3) how new applications of big data in public health challenge the underlying logics and regulatory paradigms that govern data re-uses and rights in public health practice. Drawing on critical technology scholarship, critical bioethics, and advocacy by organized networks of people living with HIV, we argue that stakeholders should enter into a new range of reform-oriented conversations about the regulatory frameworks, ethical norms, and best practices that govern re-uses of HIV public health data in the era of predictive public health interventions that target individuals.

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Introduction: HIV public health data and predictive analytics

Applications of data-driven predictive methods in clinical medicine and public health have expanded in recent decades (Rowe, 2021; Ruckenstein & Schüll, 2017). Initiatives in this area involve mobilizing massive amounts of information and advanced bioinformatics in programs that offer the promise of greater efficiency, improved services, and better health outcomes. In the United States (US), federal initiatives and integrated HIV surveillance, care, and prevention programs in some jurisdictions have begun implementing predictive analytic-informed interventions, with the goal of (re-)linking individual people living with HIV to medical care (Olatosi et al., 2019; Ragonnet-Cronin et al., 2022). These applications of data-driven technologies leverage the promise of HIV treatment-as-prevention (TasP), in which people living with HIV are prescribed antiretroviral treatment and retained in care to ensure their health and prevent onward transmission (Guta & Newman, 2021; Lloyd, 2018; Molldrem, 2020).

Preventing transmission and providing people living with HIV support to stay in care are laudable goals. However, novel applications of predictive analytics in HIV programs raise questions about the role of big data in public health and the potentially harmful effects of classifying people living with HIV in hierarchical frameworks that separate 'good' or compliant biomedical subjects from 'bad' or medically noncompliant persons (see, Hussain & Bowker, 2021; Lloyd, 2018; see also Rowe, 2021). In this commentary, we describe ethical problems arising from big data interventions in HIV surveillance and suggest some potential pathways for reform. We orient our critique within critical

bioethics and critical technology scholarship that describes how big data approaches can harm marginalized groups while also sustaining or worsening systems of domination that drive the HIV/AIDS epidemic, such as institutional racism, neoliberal capitalism, and mass incarceration (Benjamin, 2016; Geary, 2014; Hedgecoe, 2010; Mollirem & Smith, 2020; Rowe, 2021; Stark & Hutson, 2022; Sun et al., 2020). We define 'public health' as the full range of institutions that facilitate the creation and use of knowledge to improve population health, often with the aim of managing and preempting risk.

What are predictive analytics?

Big data methods generally aim to 'extrapolate the future ... based on the past' by using stored information that enables 'data-driven machine learning algorithms [to] process our collective data traces in order to discover underlying patterns' (Chun, 2011, p. 9). Predictive analytics have increasingly been used by governments and firms to understand populations and to reshape individuals' behaviors through targeted interventions. For example, predictive technologies have been mobilized by police services in programs that utilize data about individuals' past behaviors to make inferences about their likely future behaviors, with the aim of predicting potential criminal activity before it occurs (Brayne, 2021; McDaniel & Pease, 2021). Commercial and health-care organizations have also increasingly used predictive approaches to generate findings about consumer populations and to identify disparities (Adler-Milstein et al., 2017; Elmer, 2004). The integration of once-separate data infrastructures to enact these programs generate what Haggerty and Ericson (2000) call 'surveillant assemblages' where people are reconstituted as 'data doubles' classified according to personal attributes that may connote risk, thus enabling new strategies of control that can have both beneficial and harmful effects (see also, Deleuze, 1992).

Health-related applications of predictive analytics are undertaken with the intent of improving outcomes, including identifying ways of better linking people to services. However, big data initiatives that mobilize predictive analytics to anticipate individuals' future health-related behaviors are also part of broader trends in the emergence of forms of 'health surveillance' that, as French and Smith (2013) describe, could result in discrimination and greater marginalization for structurally disadvantaged populations (see also, Mollirem & Smith, 2020). We now consider and analyze two cases, which raise concerns along these lines.

Cases: HIV predictive analytics in South Carolina and Illinois

Predictive analytics have recently been used in HIV public health programs in the US states of South Carolina and Illinois. In both cases, research teams and public health personnel utilized information about people living with HIV held in state data systems to classify people based on their perceived risk of transmitting HIV or falling out of care.

In South Carolina, researchers worked with state government agencies to create an 'integrated data system' that combined data about people living with HIV with electronic health record data from multiple health-care systems and over 25 state government datasets (Olatosi et al., 2019). Among many data points, their model included history of substance use, history of mental health service utilization, history of incarceration, and 'childhood characteristics' such as contact with social service agencies while a minor, which the authors treated as predictors of social vulnerability (Olatosi et al., 2019, pp. 5–6). These data were combined in a model that aimed to identify people living with HIV who appear to be most likely to fall out of care (Olatosi et al., 2019). In developing this program, the authors consulted with a state HIV community advisory board and employed a transparency framework designed for predictive health interventions.

In Illinois, researchers used predictive approaches to 'forecast' the growth of HIV transmission clusters, ultimately issuing recommendations for new forms of 'cluster-prioritized' prevention outreach aimed at people in the fastest-growing clusters. The state department of public health shared

de-identified HIV surveillance data with the researchers, such as demographics, age at diagnosis, date of diagnosis, HIV genotype (also called ‘molecular’ data), and transmission risk factors. The study team then analyzed the data using HIV-TRACE software (Ragonnet-Cronin et al., 2022). A version of HIV-TRACE is also used by health departments in molecular HIV surveillance and cluster detection and response (MHS/CDR) prevention activities, which analyze individuals’ HIV genetic sequence data to track how different individuals’ HIV is evolving in relation to each other, thus helping to identify and reach out to people in faster-growing transmission networks (see, Molldrem & Smith, 2020). Ragonnet-Cronin et al. (2022) ultimately recommended more precise ‘cluster-guided prioritization’ in MHS/CDR, a strategy that would drive more prevention resources into molecularly-defined clusters which the authors’ model forecasted were likely to grow faster.

These cases demonstrate two ways that predictive analytics are being mobilized in HIV public health programs. In the first case, researchers developed a model that aggregated many sources of information to predict patterns of care. In the second case, molecular HIV data and other state HIV surveillance data were used to develop approaches for predicting cluster growth. Both cases raise important questions related to how people are categorized in new HIV public health data infrastructures and interventions, and how data are stored, shared, and used, with implications for ethics, regulation, and rights.

Discussion of cases

Classifying people

When applied in public health programs, predictive analytics generate new hierarchies of classification that could be organized along discriminatory lines or otherwise exacerbate the sometimes-harmful ways that people are categorized in data infrastructures. These systems necessarily function through classifying. By identifying people’s probability of falling out of care or of transmitting HIV, predictive models create new forms of institutionally defined deviance (Hussain & Bowker, 2021; Rowe, 2021). Processes of classifying people in relation to HIV risk map onto a growing trend in the TasP era, where continuous monitoring of viral load to ensure retention in care is leading to new forms of socio-legal and biomedical privilege for people living with HIV who can maintain a suppressed viral load (Guta & Newman, 2021; Lloyd, 2018; Molldrem & Smith, 2020; Molldrem, 2020).

What is unclear from our cases is what happens once a person is predictively classified as a potentially problematic or ‘deviant’ biomedical subject in an integrated infrastructure. How are these individuals treated differently by health professionals and health systems following classification, and do these classifications creep into other systems (Sun et al., 2020), such as law enforcement, employment, or health insurance? Are persons reclassified or further classified based on ‘good’ or ‘noncompliant’ behaviors, and under what conditions could a person challenge the category assigned to them? These issues warrant further empirical study.

Combining and sharing data

The promise of big data hinges on combining data in new ways to develop predictive models (Chun, 2011; Haggerty & Ericson, 2000). The creation of predictive public health data assemblages builds upon existing infrastructures and requires partnerships and data-sharing arrangements between state departments of public health and other institutions. This often takes place through health departments entering into opaque data-exchange agreements with other state agencies, correctional facilities, and other entities (Krupar & Ehlers, 2017; Molldrem, 2020). Combining demographic data, clinical lab results, and other information raises problems related to trust and privacy that public health ethicists and HIV stakeholders have highlighted (Bernard et al., 2020; Molldrem & Smith, 2020; Spieldenner et al., 2022; Watson et al., 2022). While combining data is undertaken with

the promise of optimizing benefits, these practices also carry risks of intensifying surveillance for marginalized and already-over-surveilled communities in ways that could amplify harm or cause unintended consequences (Benjamin, 2019; Newman et al., 2020).

The risks associated with classifying people and combining data in public health systems are amplified when data are shared beyond their initial context of collection, a phenomenon called ‘function creep’ (Sun et al., 2020). It is reasonable to suggest that some people with criminal records, who rely on poverty programs, or who come from minoritized populations would have well-justified concerns about their data being re-used in the ways described in the two cases (Guta et al., 2018; McClelland, 2019). Further, while providing people living with HIV the ability to consenting to opt out of data re-uses is not currently part of US public health programs, it is likely that many people would not consent to these data re-uses if asked (see, Benjamin, 2016; Buchbinder et al., 2022; Newman et al., 2020; Rudolph et al., 2020).

Applications of big data in public health that aim mainly to improve individual health challenge the underlying paradigms that govern public health

We suggest that uses of predictive analytics in public health programs could undermine the underlying epistemologies, logics, and regulatory frameworks that have historically provided justifications for public health agencies’ uses of individuals’ data. The traditional underlying logic governing public health is that interventions, regulations, and ethical frameworks built to support public health interventions justify the use of individuals’ data on the basis of promoting *greater public benefit*, as opposed to *improved individual outcomes* (Lee et al., 2012). However, HIV public health interventions that utilize predictive analytics are increasingly promoted on the basis that they will target and improve the health of *individual people living with HIV* rather than aggregate *population-level health*. Precipitating causes for this shift include the digitization of health systems allowing for more advanced forms of data re-use to target individuals, TasP, and the opening up of HIV surveillance data for prevention outreach in ways that blur clinical and public health imperatives (Guta & Newman, 2021; Molldrem & Smith, 2020; Molldrem, 2020; Oster et al., 2018).

Big data methods likely amplify positivist and behaviorist epistemologies in public health. The interventions in our cases involve processes of combining data, classifying people, and intervening based on individuals’ prior behaviors or biomarkers in ways that are intensely individualizing, motivated by an assumption – yet unproven and justified on promissory grounds – that this approach contributes to the public’s health (Sun et al., 2020). Although purporting to address ‘social determinants’ (Olatosi et al., 2019, p. 9), these cases focus intensely on individual behaviors in ways that suppress social, environmental, and other systemic forces that drive social determinants that disparately affect minoritized groups (Rowe, 2021). These developments arguably push past the limits of current public health regulatory frameworks that are designed to ensure *public benefit*. If public health agencies increasingly focus on individual benefit rather than population-level outcomes, the sector requires new regulatory paradigms and ethical frameworks that can accommodate these conditions.

Conclusion: toward new data rights and engagement in public health

Big data interventions might prove useful in HIV care and prevention. However, such programs are deployed in social contexts, and due to structural factors such as criminalization, institutional racism, and other systemic inequities, the contexts where public health HIV data are used to inform outreach are often not safe for the targets of those interventions; they thus require careful consideration, community engagement, and stakeholder consultation (Bernard et al., 2020). A new register of conversations about emergent uses of big data in HIV programs can help ensure that interventions are developed and rolled out ethically and safely for people living with and affected by HIV. While expansions of data uses are undertaken with benevolent intentions, they often exceed those that

traditional public health frameworks were designed to accommodate (Bernard et al., 2020; Molldrem & Smith, 2020; Molldrem, 2020; Ruckenstein & Schüll, 2017).

Uses of predictive analytics in public health ought to be accompanied by a rethinking of the rights that people should have related to their health data when those data are used for public health purposes. Just as the availability of big data tools might shift elements of public health practice into being more individualizing and less focused on population-level health, digital technologies can also be used to rethink public health practice in other ways that could benefit individuals and communities. The availability of massive amounts of interoperable data and the increasing ability to engage individuals using digital health platforms opens up new ways to conceptualize proposals such as piloting 'dynamic consent' affordances or selective opt-out features into public health data infrastructures (Benjamin, 2016; McClelland et al., 2020; Molldrem & Smith, 2020; Newman et al., 2020). The introduction of such affordances, however, would require the collective effort of many stakeholders along with federal policymaking processes that would involve public input periods followed by the issuance of new regulations.

The ethical and transparent implementation of HIV interventions that use predictive analytics can only be ensured if people living with and affected by HIV are involved in the process of design, execution, and oversight (on 'design justice', see, Costanza-Chock, 2020). This recommendation is aligned with growing literatures in critical social science, community-based scholarship, and public health ethics that are aimed at interrogating public health practices that treat new technologies as being key to ending the HIV epidemic, while also failing to consider the social and political contexts in which data-driven interventions are deployed (Bernard et al., 2020; Molldrem & Smith, 2020; Spieldenner et al., 2022).

Following these critiques, public health agencies and practitioners should enter into direct conversations with critical technology scholars, advocates, and organized networks of people living with HIV about the future of big data in HIV programs. This approach to direct and sustained community and stakeholder engagement has been called for and modeled by organized networks of people living with HIV, which have engaged public health agencies around ethical issues in new classes of data-driven public health programs (see, Spieldenner et al., 2022; Watson et al., 2022). Collaborative work along these lines can provide the basis for fostering a new range of conversations about how to respond to uses of big data in public health. Exchanges between stakeholders should explicitly include discussions about the possibility of introducing new data rights into public health programs, including the exploration of piloting consent affordances into HIV public health data infrastructures (see, Benjamin, 2016; Kaye et al., 2015; Molldrem & Smith, 2020). Further, prior to rolling out new predictive HIV analytics in public health, research ought to be undertaken to better understand whether these programs are effective at improving health outcomes, along with assessing ethical, legal, social, and community dynamics.

New conversations about public health uses of HIV data ought to focus on the risks, benefits, and effects of emergent uses of big data approaches and predictive analytics in HIV programs. While the South Carolina case study did engage an HIV community advisory board, in both cases, engagement with people living with HIV and issues that advocates have raised related to data re-uses could have been far more substantive. For example, HIV criminalization statutes exist in South Carolina and Illinois – a fact not mentioned by the authors, but which organized networks of people living with HIV have highlighted (Bernard et al., 2020; McClelland, 2019; Spieldenner et al., 2022). HIV criminalization is just one of many issues faced by people living with HIV, which include ongoing problems such as intensified policing and surveillance of Black, Indigenous, and other people of color; the criminalization of sex work, drug use, and migration; economic exploitation; and the lack of consent affordances or rights of refusal in public health programs. These issues are often coupled with lacking cultural competency by public health agencies and collaboration between public health and law enforcement (Hoppe, 2018; McClelland, 2019). These contexts of precarity and dispossession could be worsened by applications of data-driven predictive approaches in HIV programs. They thus give rise to the need for new forms of stakeholder engagement.

Big data methods in public health pose new potential risks, benefits, and unintended consequences for targeted populations, including the possibility of further entrenching existing HIV-related inequalities. Further, these methods (re-)shape public health logics and practices by introducing novel socio-technical relations between people, institutions, and regulations that deserve critical attention. Engaging critical public health scholars, ethicists, social scientists, and networks of people living with HIV will be key to understanding the impacts of predictive analytics in HIV programs. These constituencies should be at the center of the policymaking process that will determine whether and how novel data-driven approaches might be ethically and optimally implemented – or, perhaps, not implemented at all.

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