This paper describes how state and local departments of public health (DPHs) in the United States use data from blood tests ordered by clinicians for people living with HIV during routine medical visits to build HIV “out of care” lists. DPHs work with laboratories every time a clinician orders routine HIV-related bloodwork for a patient. If a person does not report bloodwork, or shows poor results, they can be placed on an out of care list. The processes DPHs use to construct and refine lists show how HIV care data changed during the 2010s, transforming from a class of sensitive information with many restrictions governing its exchange into a class of data that is accompanied by a mandate for public health actors to exchange and utilize it in a variety of programs. Re-uses of HIV care data for prevention follow confirmation that antiretroviral therapy for HIV is an effective way to prevent transmission, a paradigm called “treatment as prevention.”

DPH personnel enhance lists by conducting investigations, matching lists against medical records, utilizing people search tools such as LexisNexis, searching social media platforms, and other methods. This can include collaboration with correctional and law enforcement agencies — a concern in jurisdictions where HIV nondisclosure is criminalized. Public health re-uses of HIV data are done without consent. This paper focuses on the labor and ethics of building HIV out of care lists, drawing on archival health policy data, fieldwork with the HIV/AIDS workforce in metropolitan Atlanta, and a literature review.
DHPs use these lists in prevention programs to investigate people on the lists, to contact them, and then bring them back into HIV-related medical care. The processes used to construct HIV out of care lists show how clinical and public health HIV data changed during the 2010s, as part of the implementation of the National HIV/AIDS Strategy of the United States (Office of National AIDS Policy (ONAP), White House, 2015, 2010a, 2010b). During this period, individuals’ personally-identifiable routine HIV care data have transformed from a class of sensitive clinical information with many restrictions governing its exchange into data that public health agencies are required to collect, exchange, re-use, and utilize for increasingly advanced forms of epidemiology and direct prevention (Evans and Benbow, 2018; Fauci, et al., 2019).

Mandates from the U.S. Centers for Disease Control and Prevention (CDC) for state and local DHPs to re-use routine HIV care data for prevention in what are called “Data to Care” programs and other initiatives follow confirmation that antiretroviral treatment for HIV is a highly effective way to prevent sexual transmission (Prevention Access Campaign, 2016; Rodger, et al., 2019, 2016). This knowledge has led to the reorientation of the U.S. HIV strategy around a “treatment as prevention” paradigm (The White House, 2013; Rodger, et al., 2016; CDC, 2018a; McCray and Mermin, 2017). CDC released Data to Care guidance in 2014 to support treatment as prevention goals by bringing people living with HIV identified as out of care back into medical care and prescribed antiretroviral medications, thus improving their overall health through viral suppression while also making them effectively non-infectious to HIV-negative people (CDC, 2017a, 2014; Cleveland and Lansky, 2014).

The systematic re-use of routine HIV care data for public health prevention is the most significant transformation in uses of HIV data in the U.S. since the onset of the epidemic (Project Inform, 2012; Sweeney, et al., 2019, 2013). This is because, prior to the release of Data to Care guidance in 2014, HIV data held by DPHs — called “HIV surveillance data” — were only used for epidemiological assessment and planning purposes in most jurisdictions.

Data to Care programs facilitate the re-use of individuals’ clinical HIV data for direct prevention outreach based on their patterns of engagement in medical care and critical biomarkers such as viral load and CD4 T cell count. I draw upon the insights of social studies of HIV/AIDS that have described how new programs for managing the epidemic around medication adherence (Race, 2009) and viral suppression (Kippax and Stephenson, 2016) have created new hierarchies of good and bad biomedical subjectivity and citizenship among people living with HIV (Lloyd, 2018). I describe how Data to Care creates and enacts these new hierarchies through continuous forms of biomedical surveillance and interventions aimed at direct behavioral modification, all in the service of more effective and precise infectious disease control through the administration of enhanced public health measures and medical services to persons deemed “high risk” [2].

Using CDC Data to Care guidance, DPHs build HIV out of care lists using clinical data sent to them by testing laboratories every time a medical provider orders routine bloodwork for an HIV patient (CDC, 2017a; Castro and Lansky, 2013; Cleveland and Lansky, 2014). Under current standards of care, people living with HIV ideally receive CD4 T cell and viral load tests at least twice per year (Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (HHS) and HIV/AIDS Bureau, 2014). CD4 T cell counts are an indicator of immune health; viral load is a measure of disease progression and infectiousness (Gardner, et al., 2011; Rodger, et al., 2016). While the well-being of people living with HIV is not reducible to these biomarkers, they are often used as proxies to assess the health of people living with HIV at the individual and population levels — a tendency that has been critiqued (e.g., Guta, et al., 2016).

Data to Care guidance also provides frameworks for enhancing HIV out of care lists by conducting public health investigations, which can include matching out of care lists against other sources of data held by social service organizations and government agencies, exchanging data with these institutions, as well as direct outreach to individuals and their medical providers. Entities that DPHs typically partner with in Data to Care investigations include safety net healthcare organizations, federally-funded Ryan White programs (payer of last resort for HIV care in the U.S.), Medicaid and Medicare programs, and correctional facilities (e.g., Sweeney, et al., 2013; Dombrowski, et al., 2017). Data to Care has accelerated the pace, volume, and acceptable range of uses of clinical HIV data for public health purposes (CDC, 2018a, 2017a, 2017c, 2014). In this article, I explain Data to Care as it is constituted in U.S. federal policy, as it has been explained in the peer-reviewed literature, and as it was implemented by the State of Georgia DPH from 2014–2018. In the conclusion, I propose some modest reforms with the dual aim of fostering greater transparency in the administration of Data to Care programs and at providing people living with HIV greater control over the terms of their engagements with these programs through the creation of technological affordances for consent and “informed refusal” (Benjamin, 2016).
Data and methods

Data for this article were primarily gathered during a larger study involving over two years of ethnographic fieldwork with the HIV/AIDS, LGBTQ health, and health information technology (IT) communities in metropolitan Atlanta starting in 2016. This project also involved extensive health policy analysis in these areas focused on federal policy as well as state and local health policy in Georgia and metro Atlanta. Herein, I analyze data from three sources: (1) federal, state, and local Data to Care program materials; (2) fieldwork data from the larger ethnographic study; and, (3) peer-reviewed publications about Data to Care.

Health policy data analyzed for this article included technical guidance and organizational protocols related to the implementation of HIV Data to Care, with an emphasis on CDC guidance released beginning in 2014 and materials produced by Georgia DPH and other state and local agencies in metro Atlanta (e.g., Georgia Department of Public Health, 2016; Fulton County Task Force, 2017; Fulton County Ryan White, 2017). Data also included related materials such as CDC funding announcements for state and local public health agencies, HIV integrated planning guidance for state DPHs (see, Harrison, et al., 2018; CDC and HRSA, 2015; CDC, 2017b), position statements and publications about Data to Care from civil society groups and public health professional associations who helped to craft Data to Care policy (e.g., National Alliance of State & Territorial AIDS Directors (NASTAD), 2015), and a consensus report about Data to Care produced in collaboration with researchers, civil society advocates, and other stakeholders (Project Inform, 2012). Most materials were “grey literature,” defined as “[t]hat which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers” (Fourth International Conference on Grey Literature, 1999).

Peer-reviewed literature analyzed included 30 articles published between September 2013 and September 2019, including a 13-article supplement on Data to Care published in the Journal of AIDS in September 2019 (see the Appendix). This review encompassed all articles that I could locate that were published after CDC’s intent to launch Data to Care was announced in the peer-reviewed literature by Sweeney, et al. (2013) and which explicitly refer to CDC guidance. I generated this census by searching “Data to Care” with “HIV” in four academic article database aggregators, cross-referencing results to construct the final list. I included research articles and editorials, and did not exclude based on any criteria other than that the article appeared in a peer-reviewed journal and made some aspect of Data to Care its primary object of analysis. I excluded articles on pilot programs published before 2013 from the systematic review (although I cite several), articles that describe Data to Care without mention of CDC guidance, and articles that mention Data to Care but do not make it central to their analysis.

Fieldwork data included field notes and transcript data from 12 semi-structured interviews with 11 HIV professionals who were involved in implementing Data to Care in Georgia. These personnel were employed by either Georgia DPH or a partnering clinic. Job titles were changed and replaced with analogous ones to better conceal participants’ identities.

To organize and analyze data, I employed Thematic Analysis (Braun and Clarke, 2006; Braun, et al., 2018), poststructural policy analysis (e.g., Lancaster, et al., 2019), and strategies of textual reading and re-assemblage that draw on feminist Science and Technology Studies [3]. This approach recognizes that the actions or published findings of health practitioners and social scientists do not only reflect or influence pre-existing realities, but also help to shape reality (Law, 2009, 2004; Holt, 2013). This method requires cataloguing and drawing on a wide range of different kinds of evidence (e.g., grey literature, peer-reviewed publications, field notes, and transcripts). It “triangulates” [4] between multiple sources of data that (1) have been generated using different methods (e.g., policy analysis and ethnography); (2) reflect the diverse interests and perspectives of the actors being studied (e.g., healthcare professionals, policy-makers, and grassroots advocates); and, (3) come from varied temporal perspectives (e.g., future-oriented statements, accounts that temporally coincide with the source’s creation, and retrospective reflections).

This approach requires engaging in archiving practices that Michel Foucault (1996 [1966]) describes as archaeological. It demands retrieving, cataloguing, (re-)reading, and excerpting documents, along with the ongoing manipulation and annotation of text and images from published material, fieldwork data, interview transcripts, and notes. I copy and paste content from primary sources into digital notes documents and spreadsheets that I organize, annotate, and code by topic and theme. I regularly revisit and reorganize these materials. I also print hard copies of select materials, annotating by hand and employing scissors and tape to rearrange data in formats that resemble collages and scrolls, thus facilitating the identification of themes across different types of data. During data analysis, I write analytic memos, which I later convert into article sections. Drafting is done using word processing software as well as pen and
paper. This practice of textual storage, manipulation, coding, (re-)assemblage, and writing generates deeply contextualized analysis.

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**Data to Care and the history of U.S. HIV surveillance**

Since the 1980s, state DPHs (and some large city and county DPHs) have operated infrastructures called “HIV surveillance systems,” which track new infections and maintain a census of all people living with HIV in their jurisdiction who have had a positive HIV test (Cohen, 2014). Data from jurisdictional surveillance systems are reported to CDC in a de-identified fashion and are the foundation of the National HIV Surveillance System. Since 2008, data held by jurisdictional surveillance systems have been connected to first and last names (Cohen, 2014). Supported by mandatory reporting requirements set by state and federal public health laws, HIV surveillance data have historically been used to track major incidents such as new HIV infections, deaths, reports of AIDS-defining conditions such as Kaposi’s Sarcoma, and progression of cases of HIV to AIDS (Cohen, 2014).

*Figure 1* contains a diagram of the Georgia HIV Surveillance System, provided to me by a Georgia DPH interlocutor and included in public presentations by employees of the Georgia HIV/AIDS Epidemiology Section.
I present this diagram to demonstrate the complexity of HIV surveillance systems; it is not designed to be understood in its totality. Rather, the diagram must be referred to regularly so that the viewer, operator, critic, or reader can generate partial understandings of the system. This is how HIV surveillance practitioners in Georgia utilize the diagram. For example, a copy was taped above one interlocutor’s desk during my fieldwork, above her computer screen, for ease of reference. Rather than a neat representation, the diagram functions as what Alexander R. Galloway describes as an interface: a kind of interactive visual environment that allows one to dynamically explore an infrastructure by observing its various elements in relation to one another in the form of a diagram [6].

Following the issuance of a Presidential Executive Order in 2013 (White House, 2013) along with guidance sent by CDC to DPHs later that year (Castro and Lansky, 2013), all U.S. state and local HIV surveillance systems began collecting data from routine bloodwork tests ordered by clinicians for patients living with HIV. Data are reported to DPHs mainly by testing laboratories. Since this time, jurisdictional HIV surveillance systems have been required to use these data to facilitate what is often characterized as “real-time” epidemiology using an “HIV Care Continuum” framework. The Care Continuum is a model for tracking rates of engagement in HIV-related medical care and rates of HIV viral suppression in a jurisdiction (CDC, 2018a; Gardner, et al., 2011). Figure 2 contains an HIV Care Continuum for the Atlanta metro area; it reports rates of engagement in care and viral suppression using 2015 lab report data from the state surveillance system [7].

Viral suppression is defined as an individual’s last viral load test registering less than or equal to 200 copies of HIV virus per milliliter of blood plasma (CDC, 2018a; Rodger, et al., 2019, 2016). Becoming virally suppressed or “undetectable” means that an individual has effectively no risk of passing on HIV sexually, and significantly reduced risk via other transmission routes (McCray and Mermin, 2017; CDC, 2018a; Prevention Access Campaign, 2016).

In 2014, following a period of program piloting and consensus-building (e.g., Project Inform, 2012; Messer, et al., 2012; Sweeney, et al., 2013), CDC released Data to Care guidance instructing DPHs to use clinical bloodwork data held in HIV surveillance systems to provide direct prevention services to people identified as likely being out of care or in need of assistance due to poor CD4 T cell or viral load test results (CDC, n.d., 2014; Cleveland and Lansky, 2014). Under Data to Care guidance, if consistent bloodwork is not reported for a person, or if they report suboptimal
biomarkers, DPHs are encouraged to place them on an HIV out of care list — also called a “not in care” list or “out of care watch list.” Figure 3 contains a screenshot of Georgia DPH’s HIV Out of Care Watchlist (OWL) Notification Portal and logo. The OWL is represented by Georgia DPH with the image of a wise and watchful little owl, who sits perched in the “O.”
This low-quality imagery is not used in public communications. It is only viewable by health workers who have access to the OWL infrastructure.

Because HIV surveillance and prevention work is done under public health law, Data to Care programs do not require consent from people living with HIV, nor can people living with HIV opt out of these programs (Wertheim, et al., 2019; Lee, et al., 2012; Project Inform, 2012; Sweeney, et al., 2013). In later sections, I explore ethical problems posed by this, particularly regarding how Data to Care programs intersect with correctional and law enforcement institutions. This is a recognized concern in jurisdictions where HIV nondisclosure or transmission is criminalized (McClelland, et al., 2019; Galletly, et al., 2019). I argue that HIV Data to Care programs, as currently constituted, are out of balance with the public health mandate to weigh individual rights and benefits against the public good afforded by interventions (see Fairchild, et al., 2008, 2007; Buchanan and Miller, 2006). Drawing from the work of critical digital studies scholars such as Ruha Benjamin (2016) on “informed refusal” and the growing literature on “dynamic consent” platforms (Williams, et al., 2015), I suggest some pathways for reform aimed at introducing mechanisms for consent and refusal into Data to Care programs. Such changes could provide people living with HIV greater agency over how their health data are re-used by public health agencies, and thus over their own well-being.

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**Theorizing Data to Care: A “feedback loop to surveillance”**

HIV surveillance professional and Science and Technology Studies scholar Martin Holt employs the notion of the “looping effects of human kinds” from philosopher of science Ian Hacking (1995) to conceptualize HIV surveillance. He describes how surveillance not only measures the epidemic, but also shapes how it is constituted in reality. Holt writes that surveillance is

(part of a circuit which both identifies problems or targets for intervention and provides a mechanism through which the success or otherwise of interventions may be monitored. This circuit is, in effect, a desired and sanctioned “looping effect” between the system of behavioural surveillance and the people counted and classified within it ... Changes or shifts in practice are then hoped to be seen in subsequent rounds of surveillance. This is a looping effect that HIV prevention specialists want to exist, even if it is uncertain how well it works. [8]

CDC likewise characterizes HIV Data to Care as a “[f]eedback loop to surveillance” [9]. Figure 4, excerpted from a CDC “Data to Care Toolkit” [10], visualizes the loop.
As Holt suggests, this feedback loop both measures outcomes and produces new realities that are specific to Data to Care. The loop does this through the demarcation of high-risk and low-risk subject-positions, determining which people living with HIV are out of care — and therefore likely to be infectious and/or in poor health — and then reaching out to them. People living with HIV who are never identified as out of care are still part HIV surveillance, but they do not enter the Data to Care feedback loop.

As a program designed to support treatment as prevention strategies, Data to Care thus enforces new boundaries of acceptable conduct for people living with HIV. Data to Care programs are part of broader developments in the governance of HIV that yoke safety to medication adherence [11]. They create new parameters of good behavior that valorize and reward individuals who sustain a suppressed viral load through daily medication adherence, while also acting directly on those who are not able to do so by targeting them for additional support services (Guta, et al., 2016; Lloyd, 2018). However, many people living with HIV are unable to sustain viral suppression even when taking antiretroviral therapies, owing both to physiological factors and socially-determined reasons related to ability to access services (e.g., Kiweewa, et al., 2019; Krüsi, et al., 2010). Other people living with HIV delay, interrupt, or decline to initiate antiretroviral treatment for a range of reasons (Persson, et al., 2016). These people living with HIV — unable or unwilling to comply with the terms of new public health interventions — are precariously positioned in the era of treatment as prevention, being subjected to increased scrutiny and outreach by DPHs and partnering entities. While Data to Care interventions do help some people living with HIV get back into care (Dombrowski, et al., 2018a, 2018b, 2016), public health outreach to people living with HIV is often experienced as a form of intrusion (McClelland, 2019), and exists in a close relation to other forms of state control that people living with HIV must contend with in their daily lives (Mykhalovskiy, 2015), including criminal prosecution for alleged transmission or nondisclosure (Adam, 2014) or coercive forms of public health action such as house arrest (Hoppe, 2017).

From the perspective of a DPH, whether a person living with HIV is in care and/or virally suppressed is not just a
narrative that structures public health action; rather, it is a truth about specific persons determined at the infrastructural and individual levels, which subsequently reorders how specific people living with HIV are managed and acted upon by public health agencies using parameters of acceptability and deviation set by policy and law [12]. Integrated Data to Care programs that aim to advance treatment as prevention enact new forms of social control that rely on practices of ongoing monitoring and behavioral modulation on the part of both people living with HIV and the institutions that monitor and serve them (Patton, 2011; Deleuze, 1992). This form of adaptive control and behavioral change is what the Data to Care feedback loop builds up and sustains, in the name of public health (see Holt, 2013; on “building up,” see Law, 2009, 2004).

The feedback loop in practice: The four “Basic Steps for Data to Care”

CDC describes Data to Care as a four-step process: (1) constructing the initial out of care list; (2) refining and enhancing the list with other sources of data; (3) conducting outreach and providing services to people on the list; and, (4) sending data generated during Steps 2 and 3 back to the jurisdictional surveillance system (CDC, 2017a, 2014). The feedback loop closes when the surveillance system receives bloodwork data indicating that an individual has re-engaged in care. In what follows, I describe all four steps, but focus on Step 2: enhancing and refining the lists.

Figure 5 is excerpted from CDC guidance [13]. It shows the four steps, including suggestions for DPHs to undertake during each.
### Figure 5. “Basic Steps for Data to Care”

#### Basic Steps for Data to Care (D2C)

<table>
<thead>
<tr>
<th>STEP</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>STEP 1</strong></td>
<td>Identify persons out of care or not virally suppressed</td>
</tr>
<tr>
<td></td>
<td>- Create a presumptive list for follow-up (e.g., not in care (NIC) list or not virally suppressed using:</td>
</tr>
<tr>
<td></td>
<td>- Surveillance data</td>
</tr>
<tr>
<td></td>
<td>- Linked surveillance and provider data</td>
</tr>
<tr>
<td><strong>STEP 2</strong></td>
<td>Refine list by matching with available data sources</td>
</tr>
<tr>
<td></td>
<td>Examples include (but are not limited to):</td>
</tr>
<tr>
<td></td>
<td>- HIV Partner Services, STD Surveillance, State Medicaid, Department of Motor Vehicles (DMV) for locating information</td>
</tr>
<tr>
<td></td>
<td>- AIDS Drug Assistance Program (ADAP), Ryan White Care Database or EMR/clinic data for care status and other info</td>
</tr>
<tr>
<td></td>
<td>- Vital statistics, Social Security Death Index for death information</td>
</tr>
<tr>
<td><strong>STEP 3</strong></td>
<td>Conduct follow-up</td>
</tr>
<tr>
<td></td>
<td>- Health Department Model – Health department-initiated linkage and re-engagement outreach (partner services, case management)</td>
</tr>
<tr>
<td></td>
<td>- Healthcare Provider Model – Healthcare provider-initiated linkage and re-engagement outreach</td>
</tr>
<tr>
<td></td>
<td>- Combination Health Department/Healthcare Provider Model</td>
</tr>
<tr>
<td><strong>STEP 4</strong></td>
<td>Monitor continuum of care</td>
</tr>
<tr>
<td></td>
<td>- Feedback loop to surveillance</td>
</tr>
<tr>
<td></td>
<td>- Surveillance data used for analyses</td>
</tr>
<tr>
<td></td>
<td>- Data driven planning, monitoring, and evaluation</td>
</tr>
</tbody>
</table>

In Step 1, the parameters for placing an individual on the out of care list are set. Eligibility is generally determined using electronic laboratory report data, with a lack of recent labs indicating that a person has likely dropped out of care. For example, the criteria that the Georgia DPH used to build the initial OWL required an individual to not have reported CD4 T cell or viral load data in the last 15 months, with a cutoff period of up to five years (with interlocutors and print materials providing different answers about the cutoff date). However, Louisiana DPH opted to include all people living with HIV who had not reported bloodwork in the past 12 months on its out of care list (Herwehe, et al., 2012; CDC, n.d.). DPHs are given wide discretion in determining criteria for placement on an out of care list (CDC, n.d., 2017a, 2014). Notably, CDC guidance also notes that a person living with HIV does not actually have to be out of care.
care to be placed on an “out of care” list [14]. People who report high viral loads or low CD4 counts can be added to lists on the basis that these biomarkers indicate the need for additional services. Seattle/King County DPH used such an approach [15]. Alternate sources of data, such as clinical records (Hart-Malloy, et al., 2018) and pharmacies (Byrd, et al., 2019), have also been used as the basis for initial lists created during Step 1.

Step 2 begins after the initial list is created. Step 2 is an investigatory process whereby DPH personnel utilize other sources of information to improve the list by eliminating false entries and making individuals easier to locate (CDC, 2017a, 2014). Investigatory activity can include automated matches of out of care lists and/or surveillance data against medical records, pharmacy databases, and other datasets held by government agencies and commercial entities, or more labor-intensive methods that require DPH staff to search public and commercial databases, social media platforms, and conduct outreach (see, Dombrowski, et al., 2017).

In an interview, an HIV Surveillance Supervisor at Georgia DPH described one way that their staff enhanced the OWL.

**Georgia DPH HIV Surveillance Supervisor:** After we have taken — created — the list [using electronic laboratory report data], we use people search tools to update the address. You know, so like somebody whose last lab came in three years ago, that means that the last address we have is three years old, because we don’t get updates separately ... Things like LexisNexis — although we just switched to a different one. I forget what it’s called. It might be CLEAR [a subscription-based Thomson Reuters database designed to aid investigators].

Enhancements to out of care lists are focused on determining whether individuals are still alive, and if alive, that they are truly out of care. During Step 2, many people initially identified as out of care are often determined to actually be in care, with proportions varying widely by jurisdiction and investigatory methodology (e.g., Dombrowski, et al., 2017; Hart-Malloy, et al., 2019b). I now draw on the peer-reviewed literature on Data to Care, as well as fieldwork and interview data in Atlanta, to describe how a number of U.S. jurisdictions have enhanced their HIV out of care lists.

DPHs utilize public and private people search tools (e.g., LexisNexis), data sharing agreements made with healthcare and social service entities within or outside of their jurisdiction (e.g., Hart-Malloy, et al., 2019a, 2019b; Ocampo, et al., 2019; Davies, et al., 2019), database-to-database matches with hospitals and large clinics’ electronic health record systems (e.g., Herwehe, et al., 2012; Udeagu, et al., 2019), cross-jurisdictional data matches with other DPHs (e.g., Hart-Malloy, et al., 2019a; Ocampo, et al., 2019), and other methods (see Hart-Malloy, et al., 2019b). Other sources of data include tax and property records, voter registration data, and non-standard sources of information such as pet registries [16]. This work can include matches against correctional databases (e.g., Padilla, et al., 2018; Sweeney, et al., 2019; Mokotoff, et al., 2019), U.S. Immigration and Customs Enforcement (ICE) data [17], and other data from the criminal justice system. Sweeney, et al., (2018) prioritized this, writing that

> [Data to Care] programs should partner with correctional facilities to obtain data for matching purposes, because many incarcerated [people living with HIV] appeared as not in care, and this population is not always eligible for follow-up.

New forms of interaction between carceral institutions and DPHs during Data to Care and related HIV prevention programs are sources of concern among stakeholders, especially in jurisdictions where HIV nondisclosure is criminalized (Kempner, 2019; McClelland, 2019; Center for HIV Law and Policy, 2019, 2017; Hoppe, 2017). This is especially true given that the public health activity described here is done without individuals’ consent (Chung, et al., 2019; Lee, et al., 2012).

Outreach to individuals on lists and their medical providers can also be part of Step 2 (e.g., Lewis, et al., 2019; Sweeney, et al., 2019, 2018, 2013). In a Massachusetts Data to Care program, Field Epidemiologists normally housed in surveillance departments had their roles expanded to include outreach to people living with HIV and their medical providers, duties normally reserved for staff housed in prevention departments [19]. These same Field Epidemiologists also took on some duties that resembled those of clinical case managers.

Step 3 of Data to Care is focused on reaching out to people using the refined list, using either a health department model, a provider-driven model, or a combination health department-provider model (CDC, 2014). Health department models rely on traditional contact tracing and “shoe-leather epidemiology” methods involving phone calls, letters sent...
How to build an HIV out of care watch list: Remaking HIV surveillance in the era of treatment as prevention

by mail, and home visits by DPH personnel to people on out of care lists. A provider-driven model usually involves the establishment of direct linkages between a jurisdiction’s HIV out of care list and the electronic health record systems of clinical safety net organizations such as hospital Emergency Rooms and low-cost community health centers (e.g., Hart-Malloy, et al., 2018; Ridgway, et al., 2017). These “HIV Health Information Exchanges” send alerts to providers when a person living with HIV on an out of care list presents at a clinic for services (Magnus, et al., 2012; Herwehe, et al., 2012). Beginning in 2014, following the passage of a special law to enable the creation of an HIV Health Information Exchange in the state (Georgia General Assembly, 2014), Georgia DPH employed a combination provider/health department model.

Georgia’s HIV Health Information Exchange linked the electronic health record systems of several Atlanta clinics to the OWL (see Figure 3). In an interview with me at a partnering clinic, a nurse case manager described how she acted on e-mail alerts sent to her through the exchange. Alerts were sent following an automated cross-match of a patient’s name, date of birth, and social security number in her clinic’s medical record system against the OWL. She noted that while she did not understand Data to Care, she did know how to act on these alerts:

Nurse Case Manager: There are times when you do things and you don’t understand how it all works, but you still do it ...

I’m like “OK, so somewhere, there’s some master list of clients who have, you know, not been seen — I’m guessing in six months, because that’s what we consider ‘out of care’,” and — [pause] — yeah. And then it’s connected to all of these providers’ offices where, if that person’s name — ? [exaggerated shrugging motion]

It’s a mystery! [smile]

Direct outreach to people on out of care lists was also a part of Georgia’s combination HIV Data to Care strategy. In an interview at the state DPH offices, an HIV Prevention Manager involved in statewide re-linkage activities described how it was crucial for the state to connect the “technical data side” of the program to health department outreach protocols designed to locate individuals on the OWL.

Georgia DPH HIV Prevention Manager: You have the technical data side, but that’s only one component. Without the people actually going and finding these people, it’s not gonna happen. So ... what we did is, we’re starting off with the idea of an Out of Care Watchlist. We can find people who have recently fallen out of care based on a certain timeframe, provide this list to our specific districts [local county-level DPHs], and then allow [prevention personnel] to try to go out and find these people to get them into care.

Step 3 of Data to Care is completed when an individual on an out of care list has been successfully re-linked to care. At this stage, there are several evidence-based interventions that DPHs can use to help link people to care (e.g., Gardner, et al., 2014, 2007). While participation in those programs does require DPH personnel and providers to secure consent from patients, all public health activity up to this point is undertaken without consent from people living with HIV (Lee, et al., 2012; Wertheim, et al., 2019).

Step 4 closes the feedback loop. It occurs when the jurisdictional DPH receives a lab report indicating that a clinician has ordered HIV-related bloodwork for that person. This removes the individual from the out of care list. However, they can be placed back on it and re-targeted for services if their jurisdictional DPH stops receiving regular bloodwork data (CDC, 2014).

The next section focuses on how the Data to Care feedback loop has helped facilitate the integration of the care, surveillance, and prevention domains of HIV practice in the U.S. — a process that also often improves the accuracy and precision of HIV surveillance data (Dombrowski, et al., 2017). In the conclusion, I advance a critique of HIV Data to Care programs as they are currently constituted. I focus on concerns about lacking consent affordances for people living with HIV and on risks posed by new interactions between DPHs and the criminal justice system in the implementation of Data to Care.
The Data to Care effect: Integrating domains and improving data accuracy

Data to Care only became possible because of concerted efforts by the U.S. Department of Health and Human Services (HHS) to integrate HIV surveillance, care, and prevention programs at DPHs that are generally organizationally and technically separate (CDC and HRSA, 2015). Integrating these domains was key to implementing the National HIV/AIDS Strategy and was, in part, facilitated by the digitization of the U.S. healthcare system following implementation of the Health Information Technology for Economic and Clinical Health Act of 2009 (Office of the National Coordinator for Health Information Technology (ONC), 2014; Oster, 2019; on domains and data practices, see Ribes, 2019). These major federal initiatives significantly increased the data-sharing and domain integration capacities of the U.S. healthcare system, and were critical in facilitating new forms of HIV public health work that re-use routine clinical bloodwork data for surveillance and prevention (Castro and Lansky, 2013; Cleveland and Lansky, 2014; CDC, 2017a, 2014; Project Inform, 2012; Oster, 2019).

In an interview, a Georgia DPH employee who coordinated statewide HIV integrated planning emphasized how cross-domain collaboration and integration helps advance treatment as prevention.

**Georgia DPH HIV Integrated Planning Manager**: The shift has changed just because now we have integrated the planning council where we can’t just stick to prevention. We have to also look at the care aspect, because with [the Georgia Planning and Care Council], our driving force is saying that “prevention is care, and care is prevention.”

This work has focused mainly on the organizational, technical, and epistemological integration of different DPH departments and organizations within DPHs themselves (i.e., integration between surveillance and prevention departments). However, as I showed above, in my description of the relationships that Data to Care programs facilitate with DPH HIV departments and other clinical organizations such as community health centers and hospital systems, Data to Care programs have also played a role in integrating HIV infrastructures with other arms of the healthcare system and social safety net (see Fairchild, 2013; Fairchild and Bayer, 2011). Seen in this light, Data to Care is an infrastructure-building or “infrastructuring” project as much as it is a prevention program (Pipek and Wulf, 2009; Ribes and Finholt, 2009). No matter how basic a jurisdiction’s Data to Care program is — Georgia’s, for example, was far less sophisticated than those of Seattle/King County (Dombrowski, et al., 2018a, 2018b), New York State (Hart-Malloy, et al., 2019a, 2019b, 2018), or Massachusetts (Lewis, et al., 2019) — the construction of HIV out of care lists and the process of refining them and reaching out to people on them will always involve partnerships between multiple DPH HIV divisions and other institutions within and outside of the DPH coordinating that jurisdiction’s Data to Care program.

Another critical function of Data to Care is improving the accuracy of HIV surveillance data. Eliminating false entries on out of care lists during Step 2 of the feedback loop improves the overall quality of HIV surveillance data by removing people who have died, moved, or are otherwise not truly out of care (e.g., Sweeney, et al., 2019; Ocampo, et al., 2019; Mokotoff, et al., 2019). So does bringing people back into care during Step 3, and then monitoring their care through the feedback loop after Step 4. Having better data allows DPHs to allocate more resources to individuals determined to be out of care or who need of more support services.

This is a double-edged sword. People placed on HIV out of care lists and/or targeted for enhanced public health interventions are also often among the most marginalized groups living with HIV. These include transgender women (Ragonnet-Cronin, et al., 2019), people living homeless (Golden, et al., 2019), people who inject drugs (Golden, et al., 2019), gay and bisexual men of all races (and particularly Black gay and bisexual men) (Office of National AIDS Policy (ONAP), White House, 2015), people with antiretroviral drug-resistant HIV (McClelland, et al., 2019), Black women (Office of National AIDS Policy (ONAP), White House, 2015, 2010b), and people at the intersections of these subaltern positions (Crenshaw, 1991, 1989; Cohen, 1997; Nash, 2019). These are the groups who stand to benefit the most from additional services and support. However, the mobilization of many public health resources into marginalized communities without first securing the consent of the individuals targeted raises serious concerns about confidentiality, risk of exposure, and other issues that could outweigh the benefits of these interventions in many instances (see Chung, et al., 2019). This is a problem that has been inadequately studied and that stakeholders have noted as a major area of concern (Kempner, 2019).

To this point, HIV surveillance data held by DPHs and existing Data to Care programs form the basis for the next
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In 2019, these programs were announced as the “fourth pillar” of Ending the HIV Epidemic: A Plan for America, a new federal strategy (HHS, 2019; Fauci, et al., 2019). Cluster detection and response programs primarily use HIV surveillance data to identify people in “transmission clusters” of others living with strains of HIV that are closely related at the viral genetic level (McClelland, et al., 2019; CDC, 2018b; Oster, 2019). The surveillance data that DPHs use to implement cluster response have been improved by the implementation of Data to Care. As new HIV prevention strategies are implemented, stakeholders stand to gain by understanding precisely how interventions are constituted in policy, organizationally, and at the level of data infrastructure. Research findings and explanations should be presented in precise terms, centering the day-to-day work of public health activity, and should focus on both risks and benefits of programs, as I have tried to do here (see also French, 2014; French and Smith, 2013). This will help ensure that advocacy organizations and others interested in reform at the local, state, and federal levels can more effectively intervene in the rollout of programs in ways that reflect and serve the interests and needs of people who are most directly affected by these programs.

Conclusion: Carceral risks, the alien other, and reforming U.S. HIV programs

Outside of communities of professionals, including among people living with HIV and medical providers, the practice of HIV surveillance and how clinical HIV data are re-used for public health prevention remains poorly understood (McClelland, et al., 2019; Chung, et al., 2019; Kempner, 2019). Thus, I have worked to describe the many ways in which DPHs employ CDC HIV Data to Care guidelines to repurpose routine HIV bloodwork data for public health prevention. I have focused on how DPHs work with other entities to do this work, emphasizing how Data to Care requires health departments to engage in new forms of organizational and data integration, exchange, cross-matching, outreach, investigation, and domain integration (e.g., Sweeney, et al., 2019; CDC, 2017a, 2014). Taking cues from the literature on HIV criminalization and forms of administrative violence enacted against people living with HIV by DPHs during enhanced public health responses (Harsono, et al., 2017; Hoppe, 2017; McClelland, et al., 2019), and in response to activists’ stated concerns (Center for HIV Law and Policy, 2019, 2017; Kempner, 2019), I have highlighted the fact that some DPHs regularly match their HIV out of care data with data held by correctional institutions and law enforcement agencies (e.g., Padilla, et al., 2018; Sweeney, et al., 2019; Mokotoff, et al., 2019).

In at least one instance that involved the New York State and Florida DPHs, authors recommended interactions between jurisdictional DPHs and ICE to enhance cross-jurisdictional de-duplication and to locate people living with HIV who had been detained by ICE or who were otherwise known to the agency [20]. Human rights abuses by ICE have been well-documented (e.g., Woodman, 2019), and ICE is an agency that HIV activists have named in their critiques of new HIV prevention programs that involve data sharing (Kempner, 2019). Further, at least two transgender women living with HIV seeking asylum in the U.S. have died in ICE custody for reasons allegedly related to their HIV. Their names were Roxsana Hernandez and Johana Medina Leon (Garcia, 2018; Moore, 2019).

Matching public health data about people living with HIV with agencies that operate jails and prisons is an increasingly routine practice undertaken by DPHs (e.g., Sweeney, et al., 2019, 2013; Beltrami, et al., 2018a, 2018b). Such matches can lead to people re-engaging in HIV-related medical care and to better health outcomes for incarcerated, formerly-incarcerated, and recently released individuals who were not previously in care (Sweeney, et al., 2019). However, improper disclosure of HIV status in any context can lead to stigmatization and abuse, and in rare cases, to criminal prosecution for alleged nondisclosure (McClelland, 2019; Hoppe, 2017). The power imbalances and risks at play in sharing HIV data in carceral settings are extreme (Gagnon, et al., 2013; Muessig, et al., 2016; Sprague, et al., 2017), and data about a person’s HIV status can also shape other processes, such as immigration proceedings (Page, et al., 2018). Concerns about potential uses and misuses of HIV data by law enforcement, correctional personnel, and other administrative departments of the state (including DPHs) are not theoretical; they are questions of pressing importance (Wohl, 2016; Kempner, 2019).

In a media report about the death of Johana Medina Leon at an ICE detention facility, a field director for the agency is quoted as saying that

This is yet another unfortunate example of an individual who illegally enters the United States with an untreated, unscreened medical condition ... Many of these aliens attempt to enter the United States with untreated or unknown diseases, which are not diagnosed until they are examined while in detention (Moore,
Here, the officer reproduces narratives that are familiar to those with knowledge of the interwoven histories of HIV/AIDS, the politics of migration, and forms of social deviance. HIV has, since the 1980s, been associated with fears of the alien Other and with racialized tropes of illness, deviance, disease, and spread through migration (Patton, 2002, 1990; Farmer, 2006; Geary, 2014). Migrants, the poor, sexually marginalized persons, and racial and ethnic minorities have likewise long been associated with uncleanliness, “degeneration,” and communicable and infectious disease (Ngai, 2004; Stocking, 2001; Shah, 2012). These discourses — of the HIV-infected deviant, the disease-riddled migrant invader, the needle-sharing drug user, and the racialized and impoverished Other — often prop each other up, feeding panics and hateful sentiment (Farmer, 2006; Geary, 2014).

The identification of incarcerated persons, detainees, and migrants living with HIV must be a top priority of public health agencies. This is especially true since people in carceral settings are less likely to receive HIV care during imprisonment and after discharge [21], and since mass incarceration is a driver of the epidemic (Wohl, 2016). However, this work must be done with utmost caution and using evidence-based standards that do not currently exist. To this point, there is currently a lacking evidence base governing how public health and law enforcement can and/or ought to interface with one another in new Data to Care and cluster response programs; however, one is emerging. In peer-reviewed articles analyzed for this paper, multiple DPHs have implemented enhanced confidentiality measures when conducting investigations; one pilot project used IP address-concealing technology and other forms of obfuscation when conducting people search activities using public and subscription databases [22].

Moving ahead, developing a more robust evidence base to support interventions in this area should become a priority of CDC and other agencies charged with implementing Data to Care in federal policy as well as in states and municipalities. Researchers, advocates, and other stakeholders will all have a role to play in this work. While many advocates are right to be skeptical of interactions between DPHs, law enforcement, and immigration authorities (Center for HIV Law and Policy, 2019, 2017; Kempner, 2019), the rights and wellbeing of detained persons living with HIV can only be assured if individuals can be identified and offered services. As a more robust evidence base is developed, CDC and DPHs should become radically more transparent in how they implement HIV Data to Care and related programs, and particularly in how these programs intersect with law enforcement and correctional agencies. The form and adequacy of this transparency should be determined in close consultation with civil society, communities of people living with and affected by HIV, advocates, and a variety of subject-matter experts.

Concerns about new HIV data practices are compounded by the fact that HIV surveillance is done under public health law, and thus does not require consent from people living with HIV (Lee, et al., 2012; Wertheim, et al., 2019). To be in HIV-related medical care in the U.S. is to be surveilled, and to drop out of care is to be pursued for re-linkage (CDC, 2014). There are also currently no mechanisms for people living with HIV to opt out of routine re-uses of their clinical HIV data by public health departments, nor are people living with HIV offered any affordances to engage in selective forms of “dynamic consent” (Williams, et al., 2015) or “informed refusal” (Benjamin, 2016) to shape their participation in public health programs. While the U.S. health IT infrastructure has expanded, becoming increasingly interoperable and complex, thus facilitating new re-uses of individuals’ clinical HIV data for public health purposes, the policies governing consent requirements and public health data have not kept pace. In this regard, as currently constituted, HIV surveillance and Data to Care programs are evidently out of balance with the public health mandate to balance individual rights and benefits to individuals against the public health good afforded by interventions (Molldrem and Smith, 2020). Drawing on frameworks such as “informed refusal” (Benjamin, 2016), “dynamic consent” (Williams, et al., 2015), and related frameworks, CDC, DPHs, and other stakeholders should develop tools to help ensure that individual autonomy in medical decision-making are respected, and the principles of beneficence and justice are maximized, in new public health programs that re-use routine clinical HIV data for surveillance and prevention.

Providing people living with HIV mechanisms to assert controls over the exchange of their sensitive electronic health information, with specific reference to HIV, is a stated goal of HHS [23]. However, the implementation of HIV Data to Care programs has focused almost entirely on questions of integration, interoperability, data security, confidentiality, legality, and privacy (see especially, Ocampo, et al., 2019), with some limited considerations for transparency and consensus-building among practitioners (Project Inform, 2012; Sweeney, et al., 2013). Questions of fairness, accountability, transparency, consent, and refusal have not been part of the conversation until very recently (i.e., Chung, et al., 2019). Stakeholders can work to address the clear discrepancies that presently exist between consent controls that HHS and other stakeholders say that patients should have over the exchange of their HIV data and the current lack of mechanisms to put this policy commitment into practice. Priorities related to trust and shared decision-making in healthcare (Hargraves, et al., 2016) are shared by diverse stakeholders, including bioethicists and...
public health ethicists (Klugman, et al., 2018; Fairchild and Bayer, 2011; Fairchild, et al., 2008), health informatics associations (American Health Information Management Association, 2015), people living with HIV (People with AIDS Advisory Committee, 1983; AIDS United, 2018), and HIV professionals (Sweeney, et al., 2013; Oster, 2019; CDC, 2018b, 2017).

As clinical HIV data are re-used for public health prevention in increasingly advanced and varied ways, social scientists, advocates, and other stakeholders can proactively develop strategies for reform. My analysis suggests that these efforts should aim (1) to give individuals targeted by public health programs such as Data to Care greater control over uses of their health data; (2) to enhance individuals’ agency regarding their participation in these programs; and, (3) to get people living with HIV access to life-saving services on terms of their own choosing. To be effective, reforms will ultimately need to extend beyond data practices and into larger questions of healthcare reform and eliminating social inequity. The U.S. currently has the lowest HIV viral suppression among high-income countries, at an estimated 54 percent (Kaiser Family Foundation, 2019). Thus, if treatment as prevention is to be pursued ethically as a public health strategy, new HIV data practices should be accompanied by radically expanded, improved, affordable, and better-designed services that enable people living with HIV to remain in care.

Until such large-scale social transformation occurs, HIV/AIDS advocates and practitioners must work and live in the present context: one where state and federal agencies that are often openly hostile to people living with and affected by HIV are also charged with implementing enhanced responses (Cahill, 2019). In this milieu, some advocates will understandably choose not to work directly on reform projects with government agencies on the basis of these entities’ hostility and historic abuses (e.g., Chung, et al., 2019). However, advocates who take that approach are advised to be judicious in levelling judgements against others who opt to pursue strategies of direct engagement with policy-makers in order to pursue reforms. What, from one vantage, could be seen as collusion or complicity with perpetrators of state violence and repression is, seen from another, the necessary and urgent work of helping to ensure that the most vulnerable people living with HIV have access to life-saving services in contexts of extreme structural barriers to their thriving.

There are no easy paths forward or straightforward answers to the thorny questions facing our communities in the new era of treatment as prevention and public health strategies designed to support it. However, stakeholders do a serious disservice by failing to recognize these complexities, which are inherent in improving the U.S. HIV/AIDS response in a way that will end the epidemic while also honoring the dignity and wishes of all people living with and affected by HIV. At least as currently constituted, the U.S. public health response fails to do the latter, while over-emphasizing the former. A better balance should be struck.

There are many degrees between the opposing poles of uncritically accepting or promoting new HIV surveillance and prevention programs and of “[putting our] bodies upon the gears and ... all the apparatus” to “make it stop” (Savio, 1964). The interwoven histories of radical AIDS activism and more traditional forms of advocacy demonstrate that our movements have tools to grapple with — and even to take advantage of — this complexity, even in the most impossible circumstances (Epstein, 1996; Cohen, 1997; Gould, 2009; Watney, 2000; Rofes, 1998). The rapidly-evolving discourse about HIV prevention programs designed for the era of treatment as prevention is also demonstrating the contemporary movement’s capacity to have internal debates and to give platforms to a multiplicity of perspectives that will advance visions for reform aimed at benefitting people living with HIV in ways that will respect individual rights and personal autonomy (Project Inform, 2012; Center for HIV Law and Policy 2019, 2017; Kempner, 2019; Chung, et al., 2019; McClelland, 2019; Molldrem and Smith, 2020).

In this terrain of layered complexities and moral uncertainties, all stakeholders (including public health agency personnel) must be sure that they know whose side they are on. Further, the public health watchers must act with the knowledge that they, too, are being scrutinized.

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Notes


5. CDC, 2013, p. 8.


13. CDC, 2017a, p. 3.


15. Dombrowski, et al., 2018a, p. 362; CDC, n.d..


23. Office of the National Coordinator for Health Information Technology (ONC), 2015, p. 25; Office of the National Coordinator for Health Information Technology (ONC), 2019, pp. 7,426, 7,528.

References


K.K. Byrd, N.M. Camp, K. Iqbal, and P.J. Weidle, 2019. “Pharmacy data as an alternative data source for implementation of a Data to Care strategy,” JAIDS Journal of Acquired Immune Deficiency Syndromes, volume 82,
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E. McCray and J. Mermin, 2017. “‘Dear colleague’ letter announcing CDC’s position that ‘people who take ART daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner’” (27 September), formerly at https://www.cdc.gov/hiv/library/dcl/dcl/092717.html.


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Appendix: Peer-reviewed articles included in review of literature on Data to Care, 2013–September 2019


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