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Trust and Expectations of Researchers and Public Health Departments for the use of HIV Molecular Epidemiology

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Abstract

Background—Molecular epidemiology (ME) is a technique used to study the dynamics of pathogen transmission through a population. When used to study HIV infections, ME generates powerful information about how HIV is transmitted, including epidemiologic patterns of linkage and, potentially, transmission direction. Thus, ME raises challenging questions about the most responsible way to protect individual privacy while acquiring and using these data to advance public health and inform HIV intervention strategies. Here, we report on stakeholders' expectations for how researchers and public health agencies might use HIV ME.

Methods—We conducted in-depth semi-structured interviews with 40 key stakeholders to find out how these individuals respond to the proposed risks and benefits of HIV ME. Transcripts were coded and analyzed using Atlas.ti. Expectations were assessed through analysis of responses to hypothetical scenarios designed to help interviewees think through the implications of this emerging technique in the contexts of research and public health.

Results—Our analysis reveals a wide range of imagined responsibilities, capabilities, and trustworthiness of researchers and public health agencies. Specifically, many respondents expect researchers and public health agencies to use HIV ME carefully and maintain transparency about

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Author Contributions

SRM, SAV, MK and SL designed the study; CS performed the interviews; MK organized the forums; CS, SRM, SAV, MH, MK and SL analyzed the data; CS wrote the manuscript; and CS, SRM, SAV, MH, MK, and SL all edited and approved the final manuscript.

CONFLICTS OF INTEREST: All authors report no conflicts of interest with regards to the work presented here.

ETHICAL APPROVAL: All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of California San Diego Human Research Protections program (UCSD HRPP). Informed consent was obtained from all individual participants included in the study.

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how data will be used. Informed consent was discussed as an important opportunity for notification of privacy risks. Furthermore, some respondents wished that public health agencies were held to the same form of oversight and accountability represented by informed consent in research.

Conclusions—To prevent HIV ME from becoming a barrier to testing or a source of public mistrust, the sense of vulnerability expressed by some respondents must be addressed. In research, informed consent is an obvious opportunity for this. Without giving specimen donors a similar opportunity to opt out, public health agencies may find it difficult to adopt HIV ME without deterring testing and treatment.

Keywords

HIV; Molecular Epidemiology; Privacy; Genetics

Introduction

Despite rapid advances in HIV treatment and prevention, new infection rates remain unacceptably high (Bonacci and Holtgrave 2016, Rosenberg, Grey et al. 2016). Targeting limited resources to the highest risk individuals remains a major challenge of prevention efforts. Molecular epidemiology (ME) offers a way of identifying groups in which HIV is being transmitted at relatively high rates. This is possible because many RNA viruses, like HIV, evolve rapidly (Holmes 2003), creating significant viral diversity within infected individuals and across populations over time. A virus transmitted directly from one person to several others will result in a group of individuals with closely related viruses (i.e., a cluster of genetically similar viruses). Thus, viral diversity can be exploited to reconstruct the evolutionary history of the virus and infer patterns of transmission within a sampled population. Further, on a local level, aggregation and integration of molecular, clinical and demographic data offers a unique opportunity to better understand the dynamics of local transmission networks (Bello, Eyer-Silva et al. 2007, Dennis, Hue et al. 2012, Little, Kosakovsky Pond et al. 2014). Inferences made about the spread of HIV in a local sub-epidemic could then potentially be used to better target prevention and treatment resources. For example, HIV ME has been used to identify sociodemographic and geographic hotspots of HIV transmission (Mehta, Wertheim et al. 2015, Poon, Gustafson et al. 2016, Mehta, Chaillon et al. 2017, Stecher, Chaillon et al. 2018), and to direct prevention interventions (e.g. outreach to out of care HIV+ individuals, HIV screening for the HIV negative and unaware).

Data generated with HIV ME have potential for great benefit, but also pose significant privacy risks for individuals who contribute their potentially identifiable blood samples and epidemiological data for analysis. Effective use of ME in HIV prevention efforts requires collection and creation of extremely sensitive information that could allow inference of the identity of individual participants, as well as potentially implicate one or more individuals in the spread of HIV. Revelation of such data could have devastating personal consequences given that HIV exposure, non-disclosure, and transmission are criminalized behaviors or result in additional penalties in many states (Lehman, Carr et al. 2014, Centers for Disease Control and Prevention 2017b). Currently, a number of public health departments are using

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HIV ME to prioritize prevention services (Texas Department of State Health Services 2017, Brandt 2017). As ME moves from research to a tool used by public health agencies, HIV sequence data will likely be collected by health departments directly from the laboratories generating these data for clinical use, and not necessarily with notification or consent of the individual.

These technical features and the social implications of HIV ME highlight important issues in other healthcare arenas that rely on big data sets and genomic information. These issues include: the power of big data to generate new personally and socially relevant data (Peppet 2014, Evans 2016); if, when, and how to return that data to research participants (Pereira, Robinson et al. 2016, Sankar and Parker); the potential for reidentification from genetic information (Angrist 2009, El Emam, Jonker et al. 2011, Heeney, Hawkins et al. 2011, Gymrek, McGuire et al. 2013); and the problem of balancing autonomy and privacy with the protection of public health (Myers, Frieden et al. 2008, Gere 2017). In the case of HIV, prevention strategies rely on the willingness of individuals to engage with healthcare and public health institutions for testing, pre-exposure prophylaxis (PrEP), and antiretroviral therapy (ART). Adequate response to ethical concerns will be essential for maintaining public trust in the medical institutions responsible for HIV prevention and care (Whetten, Leserman et al. 2006, Graham, Giordano et al. 2010, Krause and May 2016, Kowitt, Schmidt et al. 2017).

If ME is to be part of the solution to the HIV epidemic, potential risks to individual privacy must be thoughtfully and seriously addressed. Many have argued that the best way to maintain public trust in the face of such concerns is to consult communities or stakeholders and include them in decisions about how to proceed (Rowe and Frewer 2005, Wynne 2006, Rogers-Hayden and Pidgeon 2007, Yarborough, Edwards et al. 2013, Gurwitz 2015, Aungst, Fishman et al. 2017). Several groups have now attempted to address these issues through an expert panel in the context of international research (Coltart, Hoppe et al. 2018), and through a consultation regarding molecular HIV surveillance (MHS) in US public health (Evans and Benbow 2018) which is already in place in more than 20 jurisdictions across the US. In this project we focused on determining the attitudes and concerns of key stakeholders with respect to ME of HIV.

We conducted a set of qualitative interviews with people invested in HIV prevention: individuals living with HIV, individuals at risk of becoming infected, and medical and non-medical professionals engaged in HIV prevention. In our previous report on these data we found that many of these respondents were willing to accept the risks of using HIV ME for the sake of curbing HIV (Schairer, Mehta et al. 2017). Here we report on how these respondents imagined researchers and public health agencies using HIV ME and their reactions to these possibilities. The analysis presented here suggests that many expect researchers and public health agencies to use HIV ME carefully and maintain transparency about how data will be used, for example in the form of informed consent.

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Methods

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of California, San Diego Human Research Protections Program (HRPP). Informed consent was obtained from all individual participants included in the study.

Participants

Here, we report on a subset of findings from a qualitative interview study conducted in 2015 with stakeholders in and around San Diego, CA. The overall study was designed to understand how stakeholders weigh the benefits of HIV ME with the risk of loss of privacy (Schairer, Mehta et al. 2017). For this project, we interviewed a total of 40 respondents: Individuals living with HIV (n=11), individuals at-risk of becoming infected with HIV (n=10), medical professionals (doctors and nurses working with HIV patients) (n=11), and non-medical professionals working in HIV prevention and care (e.g. activists, non-profit administrators, epidemiologists) (n=8). Here we report on the subset of our interviews that included discussion of two hypothetical scenarios. Due to the semi-structured and iterative nature of the interview guide, we did not ask all questions of all respondents. Table 1 compares the demographics of the overall study group and the respondents included in this analysis and presents the number of respondents asked about each of the scenarios discussed here.

Interviews

All interviews were semi-structured and lasted 60 to 90 minutes. Interviews followed an interview guide that moved from a general explanation of ME to increasingly specific inquiries about potential privacy concerns. (See Appendix A for the text of the interview guide.) Transcriptions of the interviews were coded in Atlas.ti (Muhr 1997). In addition to section-based codes, we developed a set of thematic codes inductively (Strauss and Corbin 1997, Saldaña 2015). These codes were then systematically applied. The initial coding task was split between CS and MK. New sub-codes were developed and applied by CS for the analysis of responses to the hypothetical scenarios described here.

To facilitate discussion of this complex and often unfamiliar research technique, the interviewer referred to a mockup of an HIV transmission network map (Figure 1). After conducting 9 interviews (5 HIV+, 2 at-risk, 1 medical professional and 1 non-medical professional), it became clear that respondents had difficulty seeing the potential for personal consequences based on the technical explanation alone. Embracing the iterative process of exploratory qualitative research, we introduced two hypothetical scenarios illustrating ethical dilemmas related to ME that had emerged from our efforts to discuss this topic with the first set of interviewees (**Table 2**).

These scenarios were open-ended as they presented ethical dilemmas that have no determined resolution. Scenario 1a was presented first in the interview, following a description of ME, and featured a hypothetical man, “John,” who is diagnosed with HIV and

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agrees to participate in a ME study. When the researchers put John into their transmission network "map" (Figure 1), they discover that John's infection is likely part of an ongoing outbreak. Interviewees were asked what researchers should do with this information. As a follow up, Scenario 1b asked interviewees to imagine that John was a university student and that his infection was part of an outbreak on campus. These scenarios were designed to probe what interviewees expected researchers to do when they produced research findings that also had public health implications.

Scenario 2 features "Steve," who is similar to John, with one key difference. We described Steve as living in a hypothetical near-future in which public health authorities use HIV ME for surveillance. When Steve is diagnosed with HIV, he is not asked to participate in research. Rather he is told that his blood sample will be sent to a public health agency to be included in an HIV ME analysis. Scenario 2 was followed with the question, "What do you think the health department might do with this information?" and followed up with a discussion about the interviewee's potential concerns. This scenario was designed to probe respondents' expectations for how public health agencies might use HIV ME and their attitudes toward such a possibility. Since conducting these interviews, Scenario 2 has become somewhat less hypothetical with the release of CDC-HIV-PS18–1802 (Centers for Disease Control and Prevention 2017a), a document intended to provide public health guidance on the use of molecular HIV surveillance.

Responses to these hypothetical scenarios are likely to reflect ungrounded assumptions about situations with which interviewees have little practical experience. Indeed, it is the presence and content of these assumptions that is the subject of our analysis. However, as with any qualitative study, the responses discussed should not be considered representative. Instead, our findings represent the range and relative frequency of responses within our sample. These exploratory findings can hopefully inform further quantitative studies to determine how prevalent these attitudes are in a larger population of potential HIV ME research subjects and professionals.

Findings

Responses to "Hypothetical Enrollee" and "University Outbreak" Scenarios

Themes identified in discussions of Scenarios 1a (Hypothetical Enrollee) and 1b (University Outbreak) included the role of informed consent, the need to investigate the outbreak further, and whether those conducting the ME need to notify the individual tested. Responses to Scenario 1b (University Outbreak) also included discussions of the potential obligation to notify the university.

Informed Consent—When discussing appropriate actions for researchers to take in the hypothetical enrollee scenario, thirteen respondents (3 at-risk, 4 non-medical professionals, and 6 medical professionals) emphasized the importance of obtaining informed consent for any possible interventions or further studies. These respondents asked clarifying questions about the content of the study protocol and consent, asserting that any potential contact or intervention should be spelled out in the informed consent.

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For example, a medical professional thought through the issues and concluded that consent would be crucial.

> Ethical obligation to intervene. <sighs> Because it's like, is somebody at risk of being harmed? You could spin it that way… Do you have an obligation? Maybe through John, but I don't know how you can just kind of swoop in to everyone else without the consent. (#304)

Others focused on the need to notify enrollees of plans to share results during consent, not because of how such results could implicate others, but because of the emotional impact of the results. For example, a non-medical professional suggested that people should have the choice to know what is learned through HIV ME.

> It might be something you could say, you know, after describing the study a little bit saying and showing them a little map like this, saying "Would you like information on what we find through this?" You know, some people might not. You know, it might make them uncomfortable. (#350)

When asked if people would be scared to know that HIV ME could reveal connections between infected individuals, another non-medical professional assumed that research participants would already be informed of that possibility, remarking,

> Well, but you're disclosing that to them when you do the informed consent for the research study, right? (#386).

Similarly, a medical professional suggested,

> It would have to be introduced at the outset of the study, because if it's in the informed consent, if it's properly explained at the outset, then people wouldn't be as freaked out. (#425)

Conduct more research—Seven respondents (1 HIV+, 3 at-risk, 2 non-medical professionals, and 1 medical professional) emphasized the importance of digging deeper into an identified outbreak to better understand its dynamics. For example, an HIV+ respondent suggested the researchers might conduct "a separate study to try to connect the dots" (#119). An at-risk respondent talked about the possibility of trying to learn more from John:

> Well, I don't know that they have an ethical obligation to intervene, I mean, as the researchers. Assuming they're studying this program or whatever it was called, I mean, I think they should definitely use this information as much as possible, talk to John and see if they can pinpoint what sort of cluster or group is he in. (#215)

Responses like these point to an expectation that researchers will reach out to their subjects in the pursuit of more useful information, rather than for individual intervention.

Intervention through notification—Seventeen interviewees (4 HIV+, 3 at-risk, 4 non-medical professionals, and 5 medical professionals) who responded to these scenarios asserted that if researchers realize that an enrollee is in a group more likely to transmit HIV, researchers should reach out and educate the enrollee about the finding. Some responses were brief, indicating an instinct that communication with the individual is necessary, such

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as, “Educate ‘em. Make sure they’re in care” (#135). A non-medical professional weighed the pros and cons before answering.

> “Boy, that’s a dilemma… They need to be aware of the fact that …there is the possibility that they would be spreading HIV to others who have previously been uninfected. I think that we’ve got to at least go that far.” (#340)

In contrast, one medical professional expressed ambivalence about the potential impact of intervention, based partly on personal beliefs and partly on experience as a clinician, stating, “No. I feel that things have to be played out on some level.” (#457). Throughout the interview, this respondent repeated the theme of providing non-judgmental care based on what the patient seeks, rather than active intervention. While unusual, this perspective is an important counterpoint to many of the approaches to intervention central to public health and HIV prevention.

When we took the scenario further by describing our hypothetical enrollee as a university student (Scenario 1b) to a subset of 23 respondents, 15 (2 HIV+, 6 at-risk, 4 non-medical professionals, and 3 medical professionals) expressed the conviction that researchers should intervene by notifying the university. In most cases, respondents replied affirmatively to the question, “Should the researchers let the university know?” Others went into more detail, like this medical professional:

> I think if you wanted to let the student health services folks know that you’ve noticed some-- a high rate of transmissions among certain groups… I think that’s relatively straightforward, and I think that would be good information to communicate to them. (#423)

Three professional respondents suggested that the researchers should notify the public health department rather than the university, as the appropriate authority to handle an outbreak. Only 4 respondents across all stakeholder groups expressed hesitation about the researchers acting on the information. For example, one prevention professional voiced concerns about the impact notification might have because of the stigma and criminalization of HIV transmission,

> Well, I mean I guess they do that with syphilis, don’t they? <whispers> I don’t know. The stigma, though, and the criminalization aspect for HIV, and then you think about the parents like, ‘Oh, my daughter got infected - we’re gonna sue the...’ I don’t know. (#386)

Response to Potential Public Health Uses of HIV ME

When we asked about a hypothetical future in which public health agencies use ME as part of HIV surveillance (Scenario 2), responses were mixed. The major themes discussed were imagined uses of ME by public health agencies; confidence or mistrust in public health or other government agencies; whether HIV ME surveillance would deter HIV testing and treatment; and the role of informed consent in public health efforts. Among the respondents who were presented with Scenario 2, 15 (2 HIV+, 2 at-risk, 6 non-medical professionals, and 5 medical professionals) expressed confidence in public health agencies to responsibly manage and use the data generated. The other half raised concerns or expressed general

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distrust in the government to handle such sensitive data. Members of all four study groups expressed each position, but professionals made up the majority of the group confident in public health agencies, while lay respondents made up the majority of the concerned group.

Imagined Uses—When asked about how public health agencies might use HIV ME in the future, many respondents referred to discussions earlier in the interview about the potential of HIV ME to enhance prevention strategies. The non-medical professional group was most articulate about these possibilities, but the ideas represented in the following quotes were echoed by members of the other groups as well. An epidemiologist working for a public health agency described HIV ME as "just…an extra piece of information" for targeting certain areas or groups (#350). Another trained epidemiologist working in research trials said, "You look at the data and analyze it, but really the whole goal of looking at data, is to come up with some type of a message, maybe policy changes" (#371). An HIV clinic administrator described HIV ME as perhaps supplementing information collected by Partner Services, a public health program that offers anonymous notification and resources for those who may have been exposed to sexually transmitted infections (Centers for Disease Control and Prevention 2016), for understanding networks of transmission:

> "This being implemented at the county level, it does give you a better sense of where the clusters are, where people are sharing partners and they might not even know it." (#360)

Such answers reflect the expectation that public health agencies would use HIV ME to continue and enhance existing approaches to HIV prevention. Many of the respondents who answered this way appeared to neither hope nor worry that HIV ME would create opportunities for entirely new prevention strategies. This attitude may be due to an awareness of existing limits on the use of epidemiological data within public health agencies.

However, some respondents were unclear about how public health agencies would use HIV ME and wondered if these data would be used for intervention strategies targeted at individuals. For example, one non-medical professional thought HIV ME would be used in conventional ways such as "deploying resources in those areas and increasing testing," but also mused about novel efforts to locate "patient zero" (#386). Another non-medical professional assumed individual intervention to be the county health department's main goal: "Based on the county they'd probably go notify people who they think are in the social network of that person because they're all about notifying and following up and making sure. That's their gig…" (#304). One HIV+ respondent suggested, without apparent concern, "They probably should have it on your license or your ID, whether or not you're positive." (#141). In the conversation that followed this comment, this respondent appeared to assume that this would be an obvious and relatively easy approach to HIV prevention.

Confidence in Public Health Agencies—Some interviewees expressing confidence in public health agencies' ability to handle HIV ME gave succinct explanations. Others implied their confidence, sometimes pointing to the sensitivity of Partner Services information routinely handled by agency employees or discussing the sorts of public health uses of the data that they would expect from these agencies with little or no criticism. Others referred to

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the rules, practices, or culture in public health agencies in support of their confidence. The epidemiologist quoted above (#350) described the practices already followed by the unit responsible for handling HIV surveillance data. The data would be collected by local agencies and sent to the county, but would not be shared with those units unless aggregated (#350). Another public health professional discussed the training and guidelines her organization uses to ensure personal information remains confidential (#360). An HIV positive man stated that public health agencies "would probably contact people because they have the right." (#119) A policy expert commented,

> I think they have legal responsibilities to be trusted with that. I think they are more accountable than other entities. (#348)

All these expressions of trust signal both a familiarity with public health agencies and an acknowledgment of specific institutional features that are expressly designed to create accountability and security.

Mistrust in Public Health Agencies—In contrast, others discussed mistrust in the government generally or, more specifically, in the government's ability to protect sensitive data. Among the respondents who expressed general mistrust, some spoke about the government as if it were a person who had no discretion, rather than a vast system of institutions with competing interests. For example, "What wouldn't they do?... Your privacy is over" (#172). One HIV at-risk respondent said, "I don't think the government should deal with any of this [HIV prevention], actually… the government's the government" (#244). This man seemed unaware that government agencies are responsible for public health services and messaging – activities he appeared to endorse elsewhere in his interview. When the interviewer asked who should be involved in HIV prevention, he responded vaguely, "people."

For others, the source of mistrust stemmed from uncertainty about the government's ability to prevent misuse of collected data. One HIV+ respondent worried that "through the Freedom of Information Act, somebody could get it [information collected for HIV ME]" (#212). This respondent perceived the Freedom of Information Act as an indication that all data collected by the government may easily be made public. An at-risk man worried about political misuse:

> If some day in the future it was determined, you know, we had a Hitler at the helm or something and there was some issue going on and that database was released and somebody came knocking on my door and said, "We know all about you and you're gone." You don't think that happens? History. (#267)

This response focused less on the use of HIV ME and more about a general sense of vulnerability associated with engaging in stigmatized behavior in an environment where personal information is or may be collected at all times. The respondent put HIV ME data in the same category as any other type of information the government might collect. Similarly, an HIV positive man worried,

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> A big fear of that is cybersecurity on those databases…You got the World Wide Web, the next thing you know you got a page that's basically … dedicated to 'Hey, this person's got HIV or this person has AIDS.' There's nothing to stop that. (#161)

Again, this respondent expressed a sense of vulnerability related to the stigma associated with HIV and the potential social repercussions.

Potential Consequences of Mistrust—While many of our respondents had participated in HIV prevention research, were committed to or invested in HIV prevention, and believed researchers should be doing all they can to prevent the spread of HIV infections, most nevertheless acknowledged potential negative consequences of the use of HIV ME for aggressive prevention efforts. In response to Scenario 2, some spoke of how others might react to being required to share not only their status, but their genetic information with public health agencies. For example,

> People aren't going to want to go and get [HIV testing] done because they feel like their rights or their privacy is taken away from them. (#252)

Others worried that for those who already avoid testing, the use of HIV ME would only serve as another reason to not be tested:

> My only concern would be that people… would be more reluctant to get tested… unfortunately, there have been a lot of barriers to people getting HIV testing and I think concerns about confidentiality is one of them. (#423)

Informed Consent and Public Health—Some respondents acknowledged that public health agencies were not required to obtain informed consent for interventions and described this as normal and expected (see for example #304, quoted above "that's their gig.") However, others felt that informed consent should not only be the norm in research, but in public health surveillance as well. One HIV at-risk respondent put it in emotional terms:

> That would feel invasive, kind of reaching into you, pulling out and then waving it for everyone to see although it's only the county that's having this information, that no one is going to have it, besides them, it still feels like-- because you didn't ask me first, I don't want to do it, and I'm going to tell my friends, "Hey, they made me do this, so don't go there". (#252,)

Though he said "only the county" would have the information, this quote emphasizes the autonomy the consent process offers to individuals. This comment suggests that some people may feel uneasy about public health agencies collecting information for HIV ME simply because the agency is not required to "ask me first." A non-medical professional had a similar thought when contemplating Scenario 2:

> Maybe if Steve could like consent, 'Okay, you can run my blood and see the social network,' but you can't like go and talk to the social network about it if that was his choice because that would breach his confidentiality. So for him, again, to have consent as to what they would be doing. And maybe they could have options and not make it so black and white. (#304)

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Distinctions Between Research and Public Health

Scenarios 1 and 2 imply a distinction between research and public health that may have been unclear to our respondents given that these interviews took place in a research clinic engaged in public outreach and by the structure of the interview guide itself. To assess this, we coded each of the 31 interviews discussed in this paper for evidence of the respondent's perception of a division of labor between research and public health.

Those who described or implied a division of labor did so in a few ways. Some discussed separate functions or activities for research and public health. For example, some asserted that, should researchers discover an HIV outbreak, the appropriate action would be to contact the public health department and let them handle it. Others stated that researchers could use the information to inform further research on the outbreak or HIV in general but could not intervene or do more than what they had specified in their protocol and informed consent documents. Still others gave sophisticated explanations of how research and public health might interact. Twenty of the 31 interviewees drew such a distinction. The other 11 interviewees did not make such a distinction clear in their discussion. For some, this was reflected in obvious confusion but, in many cases, this simply did not come up or their language was too ambiguous to be certain one way or the other. In cases of omission or ambiguity, it is not known whether interviewees failed to see this distinction or that they were less familiar with public health agencies or research.

No clear pattern linked expressions of confidence or mistrust in public health agencies with understanding a distinction from research. Within the group that did draw a clear distinction between research and public health, about half (n=11) expressed confidence in public health agencies' abilities to handle HIV ME, while the other half (n=9) expressed mistrust. Among those who drew no clear distinction from research, some expressed confidence (n=3), some expressed mistrust (n=4), and the remainder (n=3) made no definitive statement about confidence in public health. In this last group, in which both the distinction and their level of confidence were unclear, interview time was taken up by other topics.

Discussion

These findings illustrate a wide range of expectations for how HIV ME may be used in both research and public health contexts. In response to hypothetical scenarios, the stakeholders interviewed for this study imagined a set of researchers' ethical responsibilities for handling the results of HIV ME that included conducting more research, educating subjects, and sharing worrisome results with public health agencies. The respondents also imagined public health agencies using HIV ME in a variety of ways, from informing resource management to putting HIV status on state-issued identification. Some respondents expressed confidence in the ability of public health agencies to use HIV ME responsibly, but others raised concerns about the security or misuse of the generated data.

These interviews revealed two distinct sets of stakeholder expectations for researchers and public health agencies. In Scenario 1, where *researchers* hold potentially consequential information about disease threats, many respondents felt researchers would have an obligation to intervene, usually through notification of individuals or institutions. Overall,

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respondents seemed to trust researchers to do so in a responsible way that would not threaten the confidentiality of the research participants. On the other hand, Scenario 2, where such information was in the hands of *public health agencies,* sparked more conversations about mistrust and problems of privacy. Both scenarios prompted conversations about informed consent as an important means of communication and choice. Informed consent was often assumed in the research context and not assumed (though sometimes wished for) in the public health context.

The discernable difference between the discussions of researchers in Scenario 1 and public health agencies in Scenario 2 was characterized by assumptions about the respective trustworthiness of these actors. When we thematically grouped responses to Scenario 1, we found respondents imagining researchers notifying and educating individuals in a responsible manner and assuming that these activities could be addressed in informed consent procedures. In contrast, our grouping of responses to scenario 2 revealed more discussions surrounding themes of confidence or mistrust and vulnerability.

Our respondents appeared to trust researchers to act for the public good more than public health agencies. This may be linked to a perception that the mandate to obtain informed consent represents a form of oversight and accountability for researchers that is not required of public health agencies. This is also consistent with concerns about vulnerability to government misuse – an acknowledgment that public health surveillance is linked to state power in a way that research is not.

When respondents expressed expectations that researchers should intervene in outbreaks or that public health agencies should seek consent, it might be assumed that they are confused about the difference between research and public health. However, our analysis revealed no obvious link between conflation of research and public health activities and these types of expectations. Nor was such conflation clearly linked to expressions of mistrust. This suggests that expectations documented here do not simply arise from misunderstandings about the role of research and public health activities, or mistrust in these entities.

Though a consistent theme in these interviews, informed consent cannot adequately address the ethical challenges of HIV ME because findings pertain to a network rather than an individual. Collective results carry information about more than one person, whether or not they consented to participate. However, this feature of HIV ME was difficult for many of our interviewees to grasp, calling into question the adequacy of informed consent for managing the risks of data return. In the case of HIV ME, the real possibility of reidentification is especially consequential because failure to disclose HIV status, with or without HIV transmission, is criminalized in many states (Lehman, Carr et al. 2014, Centers for Disease Control and Prevention 2017b). Not only may reidentification be possible through information collected with and linked to samples, but inferences endangering privacy can be made through the unique sequence of viral DNA associated with an HIV infection. While most interviewees saw the potential benefits of HIV ME for informing HIV prevention strategies, fewer interviewees seemed to appreciate the limitations of informed consent in this context. However, the focus on informed consent as a mode of individual protection can

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be interpreted as a desire for public health surveillance to incorporate more opportunities for communication, notification, and choice.

Study Limitations

This analysis has a number of limitations related to the exploratory nature of the study design and our use of semi-structured interviews. Because we did not ask every respondent every question, we do not claim to have reached "saturation" – a point in the interviewing process when we notice no new themes emerging – with respect to answers to the hypothetical scenarios discussed here. This limitation especially pertains to the HIV+ group because nearly half had already been interviewed before we integrated the hypotheticals into the interview guide. Saturation is also a concern for findings from the "non-medical professional" group that was both smaller and highly diverse. Future studies would benefit from a clearer delineation of non-medical professional stakeholders in the use of HIV ME. For example, a more targeted inclusion of public health experts and agency leaders would have greatly enriched this study. While we did speak to public health professionals, we did not speak to enough of them to have a robust picture of the range of responses among this group.

Interviewees in any study are already self-selected research participants. Many of our participants were recruited through the PI's existing research network and had or were concurrently participating other HIV-related studies. This group is likely less sensitive to the issues of privacy and research participation than those who would not participate. Therefore, there may be concerns about privacy, informed consent, and the role of public health held by important stakeholders that were not captured here.

Conclusion

HIV ME is capable of revealing new information about HIV transmission networks, and in doing so generates extremely sensitive data implicating individuals in those networks. In the past, it might have been possible for public health agencies to adopt a new surveillance technology quietly, without fanfare or media attention. However, in today's climate of anxiety about privacy protections, the proper role of government, and the power of genetic information, it is unlikely that the adoption of techniques such as HIV ME for public health surveillance and intervention will go unnoticed.

This analysis points to how, for some particularly vulnerable individuals, public health agencies can come to represent governmental power that is feared and mistrusted. The recurring theme of informed consent in our interviews could be interpreted as a mandate, but might also been understood as a wish for greater autonomy in the face of state power. For many of our participants, informed consent represented an important "check" on the impulse to justify questionable research practices for the greater good. When considering a public health context, protections for individual autonomy were not so obvious to many respondents. The line between individual rights and the public health is typically navigated by administrators and legislators who assess the transmissibility and health risks associated with a particular disease threat and decide the degree of intervention warranted. However,

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the public has little awareness of the rules and institutional practices that protect individual liberties.

The people interviewed for this study were chosen because of their interest in and awareness about the HIV epidemic. The majority were excited about the potential for HIV ME to further understanding and prevention of HIV transmission. These interviews reflect a will to use this technique to improve public health among stakeholders, though the prevalence of this will is unknown. The themes brought up in these interviews in response to scenarios centered on research and public health uses of HIV ME suggest that mistrust in government and public health agencies will be key issues for stakeholders who encounter ME. Specifically, those who perceive the government as a monolith or who have little faith in public agencies' ability to protect information from misuse have good reason to avoid HIV ME surveillance. The attendant interest in informed consent underscores interest in the protection of individual autonomy as well as desire for oversight.

To prevent HIV ME from becoming a barrier to testing or a source of public mistrust, the sense of vulnerability expressed by some respondents must be addressed in ways that are real and obvious to individuals. In the research context, better attention to potential sharing of information with public health agencies in informed consent processes is warranted. This would require researchers to think in advance about what sort of information they might need to share with agencies – and the possible consequences of sharing it – should they notice an outbreak or other significant event. Addressing vulnerability is more difficult in the context of public health surveillance. One idea, suggested by these interviews, is offering a clear option to restrict the use of biospecimens presented through a process of informed consent. Not only would this provide a needed avenue for those who are uncomfortable with the technique, it would also provide an opportunity for public health agencies to communicate their intentions and privacy practices to individual members of the public. To maintain effective community surveillance, research is needed to determine the minimum depth of HIV sequencing within a population (i.e., the amount of ME) needed to adequately represent the HIV transmission network structure (Novitsky, Moyo et al. 2014). Ultimately, however, as long as exposing others to HIV and transmission of HIV are criminalized, it will be difficult for public health agencies to take advantage of the power of HIV ME without deterring testing and treatment.

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Appendix A. Relevant Sections from Interview Guide

Note: The following is the revised interview guide used for the final 31 participants in our study. Because interviews were conducted as open-ended and semi-structured, not all questions were asked with identical language, in the same order, or asked of all respondents.

Part 1: Introduction and Demographics

Today, we want to talk with you about a new technique that has been developed to study HIV we call “HIV network research.” The technique can be used in many ways that may help identify and prevent HIV infections more effectively. But there are also risks to using this technique. The purpose of this study is to talk to people affected by HIV to find out what they think about the benefits and risks of HIV network research. Based on your opinion, we want to create guidelines for how HIV network research should be used.

Part 2: Explanation of “HIV network research” technique

I’d like to explain how HIV network research works.

HIV evolves quickly enough that it is almost unique for each individual who is infected. Because the virus evolves with time, and as it moves from person to person, it is expected that the virus will be more similar between two individuals if their infections are more closely related. That is, the viruses carried by two people will be more similar if one infected the other than if they got it from two different people. Knowing this, researchers have developed techniques to determine the relationship of genetic sequences of HIV from many individuals. The extent of similarity and differences among HIV sequences allows researchers to study the movement of HIV through a community. We call this technique “HIV network research.”

HIV network research looks at how closely related a set of viruses are, but by itself, it can’t show which virus came first. If you think about it like a genetic test for a family, we would only be able to tell that a group of people were in the same family, but we couldn’t tell who was a parent and who was a child, or who were siblings rather than cousins. So the genetic sequences of the HIV cannot prove that one person gave HIV to another, only that their infections are related in some way.

But, if you add in other information, like how long a certain individual has been infected and the date when two people had sex or shared a needle, you can see how you could figure out who infected who.

HIV network research uses information that is routinely collected from people diagnosed with HIV. Researchers collect genetic information about HIV from an individual’s blood. They also may collect contact information for anyone they have had sex with or shared needles with so that the healthcare personnel can contact those people for testing. Contacting partners like this is already a routine part of how we try to prevent the spread of HIV in the US. Based on this information, researchers can create a diagram that shows how related a set of infections are.

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These diagrams look like this (show example).

- Each dot represents a person with an HIV infection
- The dots that are connected with lines are viruses that are closely related. This means that they are less than 1.5% genetically different. Unrelated infections could be up to 20% different.
- Therefore, the clusters of dots with many connections suggest that the virus traveled quickly between these people and might show an outbreak.
- The colors represent what neighborhood (zip code?) the infected individual lives in

If we add information about where people meet, these maps could reveal important information about where people may have initiated contact with the source of their infection (i.e., where they met or had sex with the person who infected them). This information could be used to plan prevention efforts, which I will tell you more about in a minute.

Q: What questions can we answer about HIV network research? During the rest of this interview, please feel free to ask any questions you have when you think of them.

Q: Does this seem like a valuable tool?

Q: What do you think people could do with this kind of information? [this is purposely vague: does the respondent talk about doctors, health officials, social workers, police, media?]

Q: How could this technique be beneficial?

Q: What problems do you see with this kind of research?

Part 3: Fictional Study Participant

I want you to imagine that there is a guy, John. John comes into the clinic to get tested for HIV+ and it turns out he's positive. He's not sure how he got it or how long ago. – he's had a few partners and just never seemed to get around to being tested.

When he is diagnosed, his doctors ask him if he would be willing to participate in an HIV network research study and he agrees, hoping it will help other young people like him.

So now imagine that John is a dot on this map. His name isn't on the map, but his zip code is, and the researchers know which dot he is so they can contact him if they need to. When they put John on the map, they find out that he is here (in a cluster), which means he is part of an outbreak of HIV. Maybe John has been unknowingly giving HIV to a lot of people. Maybe one of the people he had unprotected sex with is giving it to a lot of people. Maybe the crowd he runs with are all shooting up together and they are giving it to each other, so there is no one person who is the main cause. With this map, we don't know. But we do know that John and the other people in this cluster are doing something that is leading to a lot of new HIV infections.

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Q: What should the researchers do?

Q: Do they have an ethical obligation to do something?

Q: Should they contact John and the other study participants who are in this cluster? What should they tell them?

What if John were a student at a university and the cluster he was part of involved other university students.

Q: Should the university be notified? Would that be a breach of John's confidentiality? What should the university do with that information?

Part 4: Fictional Future Consumer

Now let's talk about another guy, we'll call him Steve. But Steve lives in Future Land. In the year 2030, Steve goes to the clinic to get tested and it turns out he is HIV+. But the doctors do not ask him to be in a study. Instead, the doctors tell him that they are required to share his blood sample and contact information with the health department so that they can track how HIV is moving in the city and contact him if he is eligible for special services. In Future Land, the health department uses the information they collect on people like Steve to make maps like this one and they have names for every dot on their map.

Q: What do you think the health department of Future Land would do with this information?

Q: What could they do that would be good?

Q: What could they do that would be bad?

Q: Do you think that Steve should have worried about his information being reported this way?

Q: If you lived in Future Land, would you be afraid to go to the doctor, knowing that your information could be used this way? Would others be afraid?

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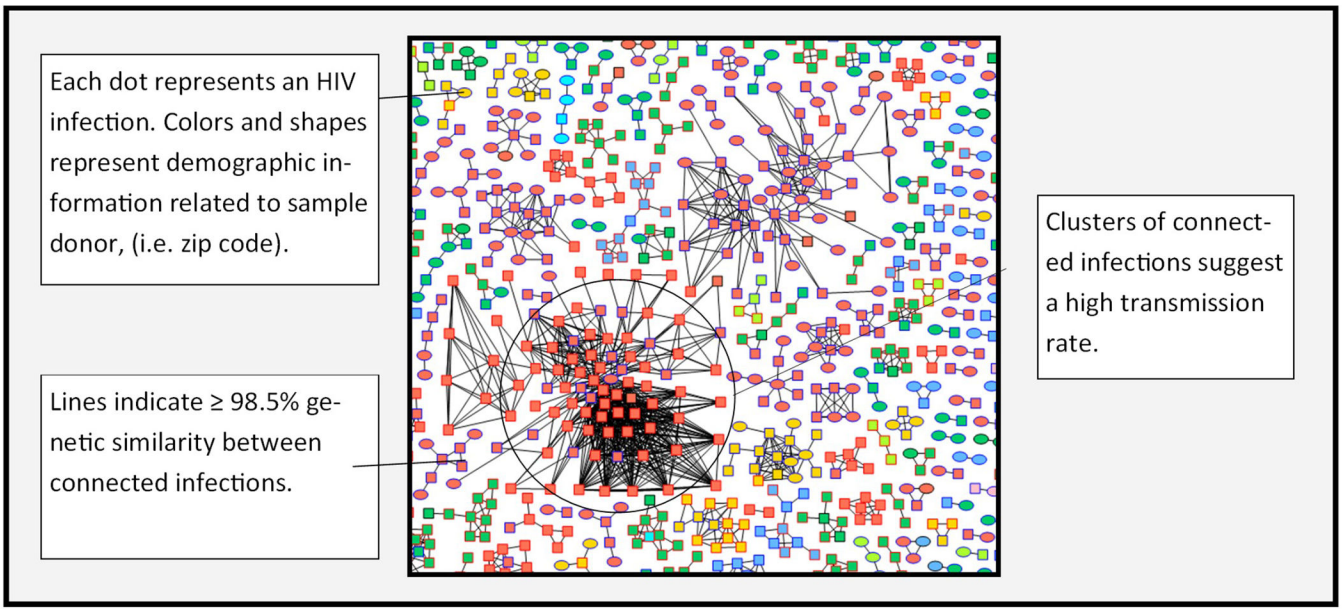

Figure 1.
Mock image of HIV ME network diagram used in interviews.

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Scenario 1a, Hypothetical Enrollee
John recently tested positive for HIV and agrees to participate in an HIV ME study. When the researchers do their analysis, it turns out John is in a cluster of individuals linked by their genetically similar HIV sequences (like one visualized in Figure 1) which indicates that he and the other people in the cluster are doing something that is leading to a lot of new HIV infections.

Scenario 1b, University Outbreak
John (as presented in 1a) is a student at a university and part of a cluster that, at least in part, was located on a university campus.

Scenario 2, Public Health Use of HIV ME
Steve tests positive for HIV, but because he is diagnosed in a future in which public health agencies conduct HIV ME for surveillance doctors tell him "Hey, we are required to report this to the health department and the health department will use your blood sample to create something like [Figure 1]."

Figure 2.
(Text box): Scenario descriptions.

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Table 1.

Description of Study Sample and Subsample

	Subset					Full Study				
Group	**HIV+**	**At risk/HIV −**	**Non-med pros**	**Med pros**	**Totals**	**HIV+**	**At risk/HIV −**	**Non-med pros**	**Med pros**	**Totals**
N										
Scenarios Asked	6	8	7	10	30	11	10	8	11	40
1a	6	8	7	10	30	-	-	-	-	-
1b	2	8	6	7	23	-	-	-	-	-
2	6	8	7	10	30	-	-	-	-	-
Gender (Men)	5	8	2	7	21	9	10	2	7	28
Sexuality										
Men who have Sex with Men (MSM)	4	8	2	4	18	7	10	2	4	23
Heterosexual	2	0		0	2	4	0	0	0	4
Not reported	0	0	5	6	10	0	0	6	7	13
Race/Ethnicity										
white	3	5	5	7	20	3	5	5	7	20
black	1	2	0	0	3	2	1	0	1	4
Latino	2	0	2	1	5	6	3	3	1	13
Asian	0	0	0	2	2	0	0	0	2	2
Not reported	0	1	0	0	1	0	1	0	0	1
Highest Education										
Less than high school	2	0	0	0	2	3	1	0	0	4
High school diploma	1	0	0	0	1	2	0	0	0	2
Some college	3	2	0	0	5	4	2	0	0	6
Bachealors degree	0	5	3	0	8	2	5	4	0	11
Some postgraduate	0	1	0	0	1	0	2	0	0	2
Post-graduate degree	0	0	4	10	14	0	0	4	11	15
Avg Age	42	37	43	40	41	43	36	47	43	41
Age Range	23–54	23–57	28–68	31–64	23–68	23–65	22–57	28–68	31–64	22–68
History of Injection Drug Use	2	0	not asked	not asked	2	4	0	not asked	not asked	4