

# Revealing Truth through Diagnostics

From disclosure laws to clinical research for novel drug  
development

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## Abstract

This article examines the changing role of ‘confessional technologies’ (Foucault 1990) over the history of the HIV pandemic, beginning when US public health departments first rolled out testing campaigns and continuing in the present day through the expansion of diagnostic practices to support the development and implementation of pharmaceutical technologies for HIV prevention. Across this decades-long history, diagnostic practices have been shaped by ethical principles, legal mandates, and research priorities, which have compelled the individual who is ‘at risk’ of acquiring HIV to speak about their sexual practices and thus reveal hidden truths about one’s self to an intimate Other (Whitacre 2018). Indeed, public health ethics have long focused on confession as a means for disciplining safe sex and managing pleasure (Race 2007) and relied on these techniques to secure resources for survival (Nguyen 2010). I argue that confessions have recently become a productive means by which to generate evidence about the efficacy of pharmaceuticals. Practices of revealing truth have contributed to clinical evidence for pharmaceutical interventions, including the use of antiretrovirals for oral HIV pre-exposure prophylaxis (PrEP). Considering the contemporary use of confessions in enabling the development of drug products and facilitating market growth, I contend that confessing should be understood as a form of labour.

## Keywords

Drug development, HIV, Subjectivity, Diagnostics, Public health.

## Introduction

Since the earliest years of the HIV/AIDS pandemic, disciplinary techniques have shaped sexual subjectivities (Race 2007). Shortly after the advent of highly active antiretroviral therapy (HAART), confessional technologies became a means for the HIV-positive subject to secure resources and gain access to therapy (Nguyen 2010). Around the turn of the 20th century, as the use of diagnostic practices expanded, confessional technologies became the central means for evaluating the efficacy of pharmaceutical interventions to *prevent* HIV (Whitacre 2018). Indeed, as diagnostics were integrated into clinical research for biomedical HIV prevention, the truths confessed by 'at-risk' individuals were made to support the development of novel products and grow markets.

This research article examines the changing role of diagnostic practices over the history of the HIV pandemic, beginning at the point US public health departments first rolled out testing campaigns and continuing through the present day as HIV testing becomes incorporated into clinical research into the biomedical prevention of HIV. This research, which seeks novel prevention methods, has involved experimental trials evaluating Truvada (FTC/TDF) as oral HIV pre-exposure prophylaxis (PrEP). Across this decades-long history of diagnostic practices, hidden truths about the 'at-risk' subject have been brought forth by ethical principles, legal mandates, research priorities, and, perhaps most of all, one's obligation to the intimate Other. Furthermore, confessional practices have become a productive means by which to generate evidence about the efficacy of biomedical methods to prevent HIV and therefore to produce products and grow markets.

From a philosophical standpoint, this ethnographic research article probes the ethics of subjectivity and intersubjective relations. On the one hand, this work continues the inquiry into the disciplinary techniques that Michel Foucault describes, including *confessional technologies*, through which one reveals hidden truths about the self (1990). Foucault explains how confession emerges in Christian ethics as a way of denouncing the self through verbalisation, and extends this observation to the human sciences, wherein the human subject no longer needs to denounce the self, but may rather constitute a new self by confessing. On the other hand, this ethnographic research is informed by the ethics of intersubjectivity that Emmanuel Levinas describes while detailing the obligation imposed on one's self by the Other (Levinas and Rolland 2003). While these ethical sensibilities have been taken up in scholarship in the anthropology of care (e.g., Garcia 2010), such work has not explored the ways in which diagnostic practices are shaped by these distinct but overlapping regimes of (inter)subjectivity. To stitch together these theories of ethical (inter)subjectivity and explore how they inform diagnostic practices, I first examine how ethical and legal

mechanisms constitute truths about the self as a private right and, second, chart ways such private rights have been split open by the ethics of public health as well as by an ethical obligation to the Other. During this brief genealogy of diagnostic ethics, I also show how the practice of disclosing truth about one's self becomes useful to generate evidence in public health, especially through research into how to prevent HIV.

By advancing inquiry into the ethical subjectivity of diagnostic practices, this Research Article contributes to scholarship in the social sciences of medicine, including recent anthropological work on medical testing and the biomedical prevention of HIV. Some scholars have provided key insights into the growing role of diagnostics in global health interventions (Street 2018) and pharmaceutical markets, including through the making of at-risk populations (Dumit 2012). They have examined the role of HIV-prevention practices in the discipline of the neoliberal subject (Race 2007) and the ways in which sexual subjectivity has been remade since the implementation of new biomedical HIV-prevention technologies (Martinez-Lacabe 2019; Thomann 2018; Sandset 2019). While exploring the ways in which biomedical prevention invites the possibility to reconstitute approaches to sex and risk (Nicholls and Rosengarten 2020), they have identified critical ways PrEP has opened opportunities to generate value in pharmaceutical markets (Atuk 2020). Building upon these important contributions, this article demonstrates how diagnostic practices have been integral to the reconstitution of both sexual subjectivity and mechanisms for producing projects in this emerging biomedical market.

Furthermore, this work deepens scholarship on clinical research participation in medical anthropology, specifically by showing how confessional practices have become the essential components of standard protocols for human subject participation in clinical research for drug development. Whereas others have shown that the experimental labour of human subjects is essential to the means of production in pharmaceutical markets (Petryna 2009; Cooper and Waldby 2014), I suggest clinical research into drug development for HIV-prevention technologies depends on 'confessional' practices. And since these confessional practices are essential to the means of production, I argue this confessional practice is a form of labour. I thus highlight the formation of 'confessional labour' and its role in making biomedical innovation possible. Specifically, I demonstrate how 'confessional labour' supports clinical research so as to develop drugs to prevent HIV. The subject is compelled to reveal truths about the self in two key ways: first, through verbal forms of confession, whereby the individual speaks truths about their sexual life; and second, through biological forms of confession, which are offered to clinical research investigators by trial subjects who submit to HIV tests. Both of these truths must be brought forth as conditions of participation in clinical

trial research and to evaluate the safety and efficacy of the experimental therapy in question. Indeed, they are vital to clinical research into the biomedical prevention of HIV.

The ethnographic observations presented in this research article have been developed through analyses of the history of and contemporary practices associated with public health interventions for HIV prevention, including through the extensive review of clinical research and public health literature, interviews with PrEP users, and participant observation in clinics where PrEP is prescribed (Whitacre 2018). However, the observations have more general relevance to other contexts, including health, sexuality, subjectivity, and the political economy of health. While the specificities of HIV should be considered, the population-level management of several diseases involves the instigation of similar regimes of diagnostic techniques whereby confessions may be solicited through related verbal and biological practices. A patient with diabetes, for example, may be asked about their consumptive practices in addition to being subject to regular blood tests. The particularity of ethics related to sexuality and appropriate sexual conduct also bears considerable weight. However, techniques of discipline and the appropriate use of pleasure are broadly applicable to the many aspects of life where ethics mediate desire and shape subjectivity, such as in the consumption of food, media, entertainment, and other alluring materials and substances.

What I aim to illustrate are the ways in which these diagnostic practices—and indeed, these forms of confessional labour—are productive in that they generate evidence in biomedical markets. I call on scholars in the social sciences to examine further ways in which confessional practices are made to be productive as emergent forms of labour that make possible the production of commodities in health or other industries. Such analyses have significant potential to deepen anthropological theory by producing insights into contemporary concerns regarding the management of health and the ways in which we are all caught up in webs of discipline and desire. These are themselves shaped by the demands of ethics, are ready to be diagnosed, and contain the potential to generate evidence to support the growth of new markets.

### **Constituting inner self of the ‘at-risk’ subject**

As the AIDS epidemic grew in the United States in the late 1980s, ethical and legal measures concerning the disclosure of HIV status simultaneously constituted the inner self of the subject as a private right and a public concern. The HIV status of health workers, for example, became subject to mandatory disclosure policies (Cruz 1991; Lenehan 1991; Pennsylvania Superior Court 1991; Keeney 1992; Scheerhorn 1995). In some jurisdictions, it was the responsibility of healthcare

workers to reveal their status to their employers. In turn, hospitals were responsible for managing information about the HIV status of their care providers (Stephens et al. 1995). As laws determined whether and how healthcare workers should reveal their HIV status, many workers developed fears their HIV status would be disclosed against their will (Reid 1994), and such requirements sparked controversy among nurses, physicians, psychologists, ethicists, and scholars of medical law (Bocchino 1990; McDonald 1989; 1990; Doe 1990; Navran 1990; Christie 2002).

These controversies also extended to court hearings about the unlawful dissemination of test results, as plaintiffs alleged that the disclosure of highly sensitive and personal information violated their rights to privacy.<sup>1</sup> In this case, the right to privacy would protect medical information, including a person's HIV status, from being shown or told to another person. Debates over the right to privacy also introduced further questions, including: should patients be required to reveal their HIV status to dentists and physicians (Perry et al. 1993)? Do provisions within the Americans with Disabilities Act (ADA) protect patients from disclosing this information (Goldberg and Sprotzer 1998)? As these debates continued, departments of public health and professional medical associations began to take sides. The New York Health Department, for example, rejected mandatory disclosure laws in 1992 (Becker 1993), thus upholding the idea that revealing one's own HIV status was the right of the liberal subject. Though institutional policies were enacted early in the epidemic to compel the subject to reveal his or her HIV status, public health departments (e.g., the New York Health Department) maintained that revealing personal information about the self, including one's HIV status, was a sovereign right of the liberal subject. Thus, in the context of HIV prevention, the self was initially constituted as that which the liberal subject has the right to reveal to another if and when he or she wills it.

At the same time, there was debate about whether the subject that submits to an HIV test should be required to receive their own test results, or whether such a mandate would disregard the individual's choice to maintain individual privacy and liberty. This was a concern, the US Centers for Disease Control and Prevention (CDC) observed, because people who might be at risk of HIV were not submitting to HIV tests and some who had completed HIV tests were not returning to receive their results (Silvestre et al. 1993). While many believed a patient would and should return for the result, others contended that 'the tested individual [would be] afforded no choice in the matter' (Closen 1991, 447). These critics highlighted that not being afforded a choice was particularly concerning because the subject would be confronted with the obligation to disclose when, for example, he or she applied for

1 See, for example, *Harris v. Thigpen*, 727 F. Supp. 1564 (US District Court, MD Alabama, ND 1990); *McCune v. Neitzel*, 235 Neb. 754, 457 NW 2d 803 (Supreme Court of Nebraska 1990).

life or health insurance; volunteered to donate blood, semen, or organs; was imprisoned; or otherwise agreed to medical or mental health services. Moreover, disclosure in these contexts could lead to significant legal, economic, and social hardship. The ‘constitutional rights of liberty and privacy’, they argued, ‘mandate that citizens be permitted to decline forced disclosure of this information’. ‘Each individual’, therefore, ‘should have the right to decide in advance whether he or she will be told of the HIV test result’ (Closen 1991, 448). Here, again, the rights of the liberal subject triumphed: it was decided that one cannot be told a truth about one’s self against one’s will.

While the right to privacy ensured the subject maintained sovereignty over the inner self, the doctor–patient relationship introduced further questions that moved beyond privacy to primarily concern confidentiality, such as: in what ways does knowing a patient’s HIV status introduce ethical conflicts for a physician (Pochard et al. 1998)? Under what conditions is a healthcare provider required to maintain confidentiality or disclose personal information (Cohen 2003)? If a patient refuses to disclose his or her HIV status to an intimate partner, do these rights and responsibilities change (Chiodo and Tolle 1992)? This set of questions—concerning as it does the obligation of a healthcare provider to maintain patient confidentiality in the case that a patient was not disclosing their HIV status to an intimate partner—was taken up by Elliot D. Cohen, who constructed an ethical framework to guide psychologists’ responses. In his article, ‘Lethal Sex’ (2003, 254), Cohen recognises that confidentiality is generally required in situations where patients ‘feel comfortable in revealing their darkest secrets’, but he also acknowledged that this ‘bond of trust has its moral limits’. He asserted such limits are crossed ‘in some cases in which HIV positive clients are sexually active with unsuspecting third parties’. Advancing these assertions, Cohen drafted ‘a model rule for the American Counseling Association’s Code of Ethics that permits, and sometimes morally requires disclosure’ (Ibid.). Cohen’s model rule about the limits of confidentiality disrupts the will of the individual subject, who would otherwise maintain the right to keep private the truth of one’s self. The rule also seeks to protect the intimate Other from harm. So, despite the sovereignty of the subject to know what one wills to know and to reveal what one wills to reveal, the withholding of that truth from an intimate Other causes the sovereignty of the individual to split open, meaning the subject then becomes answerable to another set of ethics—i.e., that which concerns and governs encounters with the intimate Other. I will refer to the ethics of this encounter as ‘intimate ethics’.



1. Photo credit: Aaron Jay Young, self-portrait taken in 2013. [www.aaronjayyoung.com](http://www.aaronjayyoung.com). Permission to reproduce photograph obtained from author.

Whereas the right to privacy reinforces the sovereignty of the liberal subject over the self, public health ethics introduce an obligation for the subject to disclose. In the US, these ethics are written into law as 'disclosure laws', which discipline the HIV-positive subject to reveal one's own HIV status to the Other. Under the terms of the law, the HIV-positive subject that does not reveal this truth about one's self to the Other becomes legally culpable.<sup>2</sup> Each year, there are numerous cases in which disclosure laws are used to prosecute the HIV-positive subject;<sup>3</sup> under the

2 Many advocates have championed laws that protect the subject from legal prosecution (Holmes and O'Byrne 2006), have promoted a public health approach to disclosure over and above criminal law, and most pointedly argued that criminal law undermines public health efforts (Galletly and Pinkerton 2006).

3 The Center for HIV Law and Policy has published a list of arrests and prosecutions for HIV exposure in the United States for the years 2008 through 2017. Though the list is only illustrative and non-exhaustive, cases number in the dozens per year.

terms of the law, people are prosecuted for charges such as ‘sexual intercourse without disclosure of HIV’. James Fyffe, for example, was ‘accused of intentionally hiding the fact that he had HIV when he had sex with a woman’ (Ferrise 2017). According to court records, several people told Fyffe to disclose his HIV-positive status to the woman, but he refused. Fyffe was charged with felonious assault. In a similar case, the defendant was ordered to register as a sex offender by a ‘judge who said he worried the defendant could have had other sex partners whom he did not tell about having HIV’ (Lynch 2017). By not disclosing this truth, these men had violated a basic tenet of intimate ethics and were therefore punished.

Law and ethics concerning the disclosure of HIV status have both secured the sovereignty of the subject over the self and imposed on the subject an obligation to reveal one’s self to the intimate Other. This latter imposition opened the subject to medical scrutiny and legal culpability. It also obligated the subject to abide by the ethics of intimacy. Thus, at the nexus of the obligation to disclose and the right not to, the inner self of the subject becomes constituted simultaneously as a public concern and a private right: it ought to be brought forth and protected, and becomes an element of the self that is known to exist but allowed to remain hidden.

## **Disclosure practices in public health research**

By researching disclosure practices, investigators could generate evidence about HIV-positive subjects and ‘at-risk’ populations. Though people with HIV could not be forced to disclose the truth about themselves, the information that the HIV-positive subject *had* voluntarily disclosed, and to whom, could be traced in research studies. Thus, as public health departments ramped up HIV testing campaigns across the United States, research into HIV prevention also began tracing disclosure practices. While initial inquiries into whether or not people were talking about their HIV status with intimate Others produced contradictory findings (Maman et al. 2003; Stein and Samet 1999; Geary et al. 1996), studies soon moved beyond questions about whether or not disclosure was happening to ask who was most likely to disclose their HIV status. Other questions accompanied this one: how is disclosure affected by other social factors, like social support and stigma? What roles do race, gender, and sexual orientation play? And, further, how does disclosure relate to health outcomes? Is disclosing associated with HIV prevention interventions, like testing, condoms and behaviour change? Also, could there be a relationship between effective treatment and disclosure practices? By tracing practices of disclosure, investigators began to compile a new body of evidence regarding at-risk individuals.

This research was supported by an influx of funding from the US National Institutes of Health (NIH), which erected a massive network of research centres and

launched multiple studies focused on HIV prevention. While this funding stream amounted to just over \$400 million in 2000, over the following decade, research on HIV prevention would reach over \$3.5 billion annually, mostly in support of investigations at the Centers for Disease Control and Prevention (CDC) and prominent medical schools across the country (NIH 2021). These investigators evaluated how people with HIV disclosed to sexual and romantic partners or family members (Marks, Richardson, and Maldando 1991; Schnell et al. 1992) and monitored differences in disclosure practices among subjects according to race, sex, gender, and sexual orientation (Serovich, Esbensen, and Mason 2007). This research found, for example, that heterosexual African-American women almost always disclose to their mothers and sisters relatively soon after receiving a positive result (Serovich, Craft, and Yoon 2007). Meanwhile, men who have sex with men disclose to both 'intimate lovers' and family members (Mansergh, Marks, and Simoni 1995); they would, however, likely take more time to talk to family members and, when they did, the ways in which they communicated their status varied significantly by ethnicity (Fekete et al. 2009).

These investigators also observed differences in how people living with HIV disclosed to their partners, friends, family members, and religious leaders or clergy (Miller and Rubin 2007). People disclosed to family and partners motivated by 'a sense of duty' as well as to seek material support. People disclosed to religious leaders, on the other hand, in order to seek advice. People hesitated to disclose to friends because of a lack of trust and, specifically, a fear that friends might tell others. Men are more likely to disclose directly to partners, while women use less direct communication methods. Overall, roughly one third of participants rely on a third party to disclose to an intimate partner (Ibid.). Through this research, Miller and Rubin produced evidence that helped characterise at-risk populations in terms of their intimate relations.

The findings from several studies (e.g., Miller and Rubin 2007) suggested that social support and stigma affect disclosure practices, so as this field of research continued to develop, research teams from federal agencies and public health departments dedicated more resources to understanding the ways in which disclosure practices were affected by different social institutions. The motivating concern behind these questions was that people living with HIV feared disclosure because HIV is stigmatised. In fact, in 2001, the CDC found that one in five Americans stigmatise HIV. Moreover, stigma was shown to contribute to bad outcomes, and such effects were particularly concerning among minority communities for whom social stresses were intersectional (Körner 2007), such as African-American women (Clark et al. 2003). Conversely, social support was positively associated with disclosure practices (Rier 2007; Kalichman and Nachimson et al. 1999).

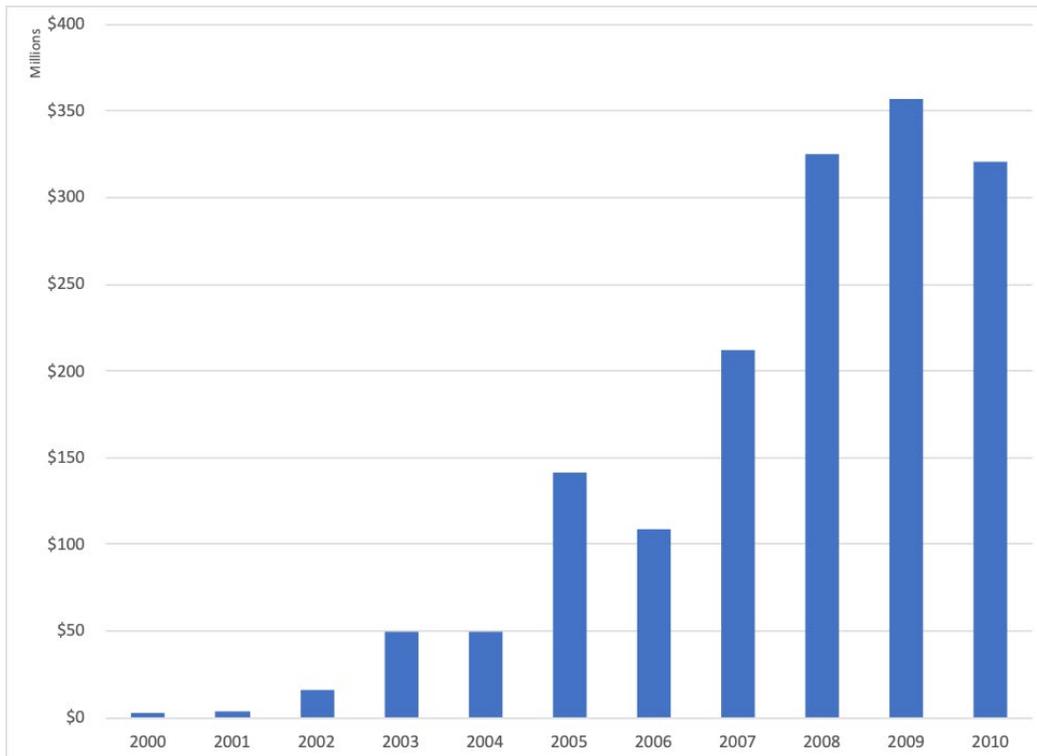
Noting the links between disclosure practices and social support, public health institutions also sought to promote social support and thus improve health outcomes (Ostrow et al. 1989). Connected to psychological wellbeing and quality of life (Chandra et al. 2003; Menon et al. 2007; Zea et al. 2005), disclosure was conceptualised as a strategy for coping (Holt et al. 1998; Vance 2006; Medley et al. 2009). Practices of disclosure and techniques for managing emotional distress were said to be associated with self-efficacy (Kalichman and Nachimson et al. 1999). People were also more likely to disclose their HIV status after counselling (Perry et al. 1993).

Another set of questions concerned the relationships between the practices of disclosure and interventions for HIV prevention, including HIV testing, counselling, condom use, and behaviour change. Some of these studies focused on provider–patient communication regarding ‘safer sex’ and disclosure (Marks et al. 2002) while others evaluated the links between disclosure, ‘high-risk’ sex, and condom use (Kangwende, Chirenda, and Mudyiradima 2009; Pinkerton and Galletly 2007a). Others tracked the relationship between patterns of testing and disclosure (Dafatry, Padayatchi, and Padilla 2007). This research also found several related benefits of disclosure: for example, one study observed that the ‘positive outcomes’ of disclosure ‘included risk reduction behavior, partner testing, increased care-seeking behavior, anxiety relief, increased sexual communication, and motivation to plan for the future’ (King et al. 2008).

Research into the relationship between disclosure practices and interventions for HIV prevention was supported by similar research into the links between disclosure and effective treatment. For a body of research that began shortly after the emergence of the HIV epidemic, at a time when no treatment was available, and continued through an era of effective treatment, important questions about the impact of treatment were coupled with social and behavioural factors associated with treatment adherence and effectiveness. By comparing outcomes before and after the introduction of highly active antiretroviral treatment (HAART), researchers including Batterham et al. (2005) were able to isolate the role of treatment within studies researching predictors and patterns of disclosure and show how treatment varied across affected populations (Siegel, Lekas, and Schrimshaw 2005). Such research also evaluated the relationship between disclosure and adherence to treatment (Stirrat et al. 2006; Klitzman et al. 2004).

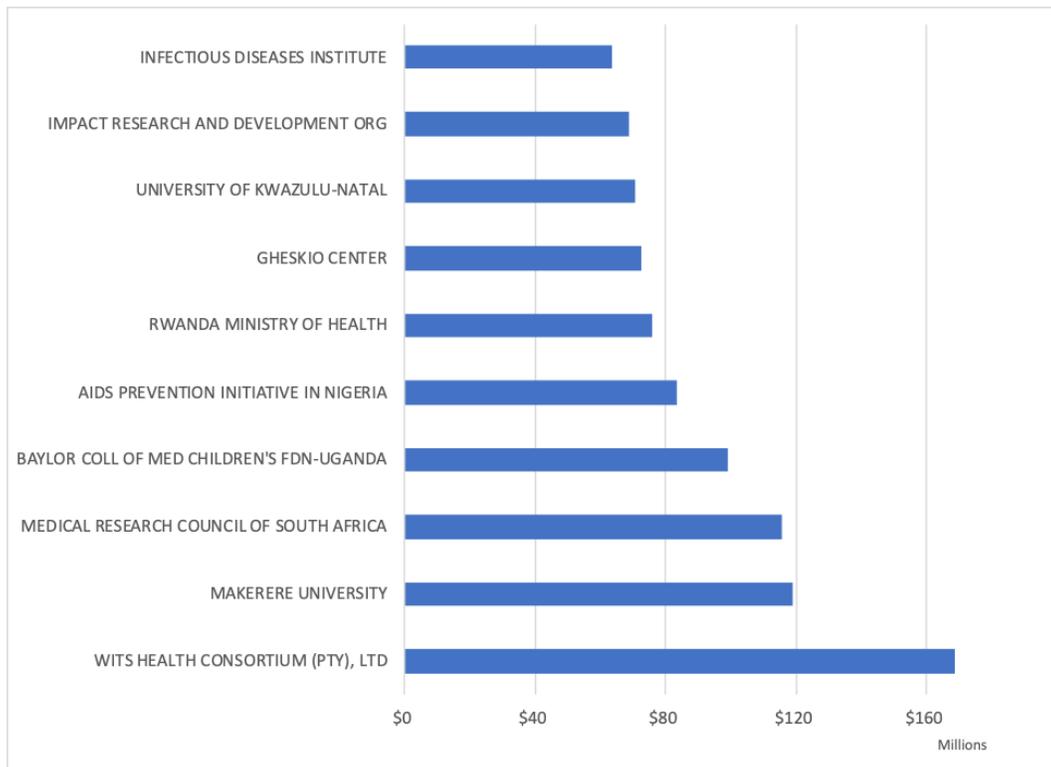
Soon after the NIH-funded public health departments in the United States began to record and catalogue disclosure practices, NIH money also began to support the globalisation of HIV prevention research in various sites around the world, where investigators continued to study the ways in which people with HIV were talking to their intimate Others. While the funding for HIV-prevention studies on

foreign soil lagged behind domestic initiatives by several years, by 2010 the NIH had channelled a total of \$1.59 billion into HIV prevention research, supporting over 1000 studies conducted in countries across sub-Saharan Africa (SSA) and Southeast Asia (Fig. 2; NIH 2021).



2. US National Institutes of Health funding for HIV prevention research conducted by organisations in SSA and SE Asia, 2000-2010 annual. Source: NIH RePORTER (NIH 2021).

Spending on HIV-prevention studies in these regions averaged nearly \$200 million annually over the following decade, and by 2020 the total funding in the region had grown to \$3.47 billion. The money was channelled to numerous research centres across the continent, but the majority went to universities in South Africa, Uganda, and Nigeria. Wits Health Consortium (Pty), Makerere University, and the Medical Research Council of South Africa were each awarded over \$100 million, and the Baylor College Of Medicine Children's Foundation in Uganda was given \$99 million (Fig. 3; NIH 2021).



3. US National Institutes of Health funding for HIV prevention studies conducted by organisations in SSA, 2000-2020 (top 10). Source: NIH RePORTER (NIH 2021).

Backed by this inflow of funding; citing previous US studies; and, in many cases, working in partnership with US research universities, investigators at research centres across sub-Saharan Africa and Southeast Asia launched numerous studies into HIV disclosure practices. One line of research focused intently on the matter of disclosing HIV status, especially to children who had acquired the virus through, for example, mother-to-child transmission. This was a prominent concern because studies had found the likelihood a mother would disclose her status to her own children was less than 50% and, among some subpopulations, lower than 35% (Simoni et al. 2000; Murphy, Steers, and Dello Stritto 2001). The 'best practices' for disclosure to children thus became a key topic (Lester et al. 2002; Moodley et al. 2006) for, among others, research teams in low- and middle-income countries such as Botswana, Ethiopia, Kenya, South Africa, and Thailand, where mother-to-child transmission has historically been high (Madiba 2016; Mengistu 2013; Oberdorfer et al. 2006; Gachanja, Burkholder, and Ferraro 2014).

Even after decades of research on the topic, medical journals continued to publish articles on the topic of disclosing HIV status to children. Reflecting the ongoing challenges associated with talking to children about their HIV status, a title for one research article published in 2013 read, 'Disclosure of HIV Diagnosis to Children: A Poorly Addressed Issue in Pediatric HIV Care' (Mengistu 2013). Another,

published in 2016, identified a lack of the skills necessary to disclose HIV statuses to children among caregivers in resource-limited communities (Madiba 2016), and a related study in Kenya summarised a prominent feeling among children about delays in disclosure with the question, ‘Why did you not tell me?’ (Vreeman et al. 2015).

In sum, by maintaining an intent focus on disclosure practices for over more than three decades, investigators have sought to determine which of their HIV-positive research subjects were revealing truths about themselves, and to whom. Further, as individuals of various demographic markers disclosed their statuses to family, friends, and lovers, US public health began to differentiate between the disclosure practices of various ‘at-risk’ sub-populations. Through this project of testing and monitoring disclosure practices, researchers generated data on the differences between distinct sub-populations and gained insight into how to improve the health of the whole population. Indeed, evidence from these studies guided the categorisation of a given individual according to his or her disclosure practices and to what they revealed to an intimate Other. Thus, by tracing disclosure practices, the field generated evidence about the behavioural practices of risky populations that could inform further public health interventions.

## **Confessional labour in clinical research**

More recently, a new formation of diagnostic practices has emerged in clinical research that evaluates biomedical HIV-prevention technologies. This set of diagnostic practices has solicited truths in different settings towards novel ends. Whereas disclosure practices compel the HIV-positive individual to reveal the truth of their HIV status continuously over extended periods, in experimental clinical research for HIV prevention the ‘at-risk’ individual is compelled to reveal their HIV status and speak about their sexual practices. These diagnostic practices are embedded in the design of clinical trials that evaluate the safety and efficacy of using oral antiretroviral tablets for oral HIV pre-exposure prophylaxis (PrEP), which began to be conducted around the turn of the 21st century. The way diagnostics were embedded in the design of PrEP trials presented a new trajectory in a long history of discipline and ‘at-risk’ sexual subjectivity. Whereas the ‘at-risk’ subject was disciplined by public health interventions to limit risky sexual practices, in clinical research for PrEP, the subject who did not submit to such forms of discipline became the ideal participant.

Indeed, one of the primary ways PrEP trials rearranged this history of discipline was reflected in the inclusion criteria for enrolment (Grant et al. 2010). To qualify to participate in clinical PrEP research, an individual was required to tell investigators that he or she was ‘at risk’ of acquiring HIV. This risk was measured

by the number of sexual partners the participant had—the higher the number, the higher the risk—and by the participant’s engagement in specific sexual practices, which varied depending on the risk group. For men who have sex with men (MSM), HIV risk was most closely associated with receptive anal intercourse. Meanwhile, for heterosexual women, risk was defined in terms of vaginal sex. For each of these groups, having sex without a condom constituted higher risk. Some study inclusion criteria also specified that a potential participant must have acquired a sexually transmitted infection or have had sex with someone with HIV. These risk criteria were evaluated within specific timeframes (e.g., the past six months). As this makes clear, the enrolment criteria for PrEP trials were defined in terms of how an individual participant managed one’s intimate life and sexual pleasure. Being ‘at risk’ of acquiring HIV was a criterion for inclusion.

Based on these inclusion criteria, one of my informants qualified to participate in a PrEP clinical trial because, as he reported to investigators, he was ‘having a lot of sex’. In particular, Lance (as I will refer to him) was having sex with multiple men, sometimes as the receptive partner and occasionally without a condom. Also, some of the men he had sex with were knowingly living with HIV. He was, for the purposes of the study, ‘at risk’, and was thus an ideal participant. While HIV prevention had tirelessly cultivated an ethical intimacy through disciplinary and diagnostic techniques and thus crafted the sexual ethics of the ‘at-risk’ subject, the subject who defied discipline became the ideal participant in clinical research for PrEP, so long as he was willing to talk about his experiences.

In clinical research for PrEP, HIV testing also became integral to the production of evidence for pharmaceutical efficacy. The main clinical end point of the trial Lance was enrolled in was HIV incidence. Thus, participating involved getting tested for HIV on a regular basis, and, by submitting to HIV tests in the PrEP trial, Lance and other participants constituted the evidence base that allowed investigators to measure drug efficacy. In particular, investigators evaluated efficacy by observing the difference between the number of people who acquired HIV in the control group and treatment group. If HIV incidence in the treatment group was significantly lower than in the placebo group, the treatment could be considered efficacious.

Lance was one of nearly 2,500 participants in this trial. All participants were asked to report to a local clinic regularly for testing and to talk to investigators about their sexual practices. By the conclusion of the trial, the investigators found that 100 participants had acquired HIV; of these, 36 had received the medication, while 64 had received a placebo. The results indicated a 44% reduction in HIV incidence. By participating in this trial, which evaluated the safety and efficacy of Truvada for PrEP, Lance and others contributed to the development of the drug through a kind of *confessional labour*. Indeed, I suggest labour in HIV-prevention trials depends

on a fundamentally confessional practice—it demands that participants reveal hidden truths about themselves through words and blood samples (both these forms of truth are made to matter for pharmaceutical efficacy). By confessing, Lance and other participants qualified to participate and constituted the evidence base. Indeed, through confessions, evidence of efficacy was established, then submitted to regulators for commercial approval. Based on the evidence produced through this confessional labour, the US Food and Drug Administration (FDA) approved Truvada for PrEP. Truvada thus became the first commercial drug product for HIV prevention.

## Conclusion

This research article has shown how diagnostic practices have historically reinforced the inner self of the ‘at-risk’ subject and opened new possibilities for producing products in biomedical markets. Since the 1980s and the emergence of the AIDS pandemic, HIV testing has unearthed secret truths about the at-risk individual. As the use of HIV tests became mandated by medical ethics and legal mandates, the inner self of the at-risk subject was constituted as a private right and a public concern, in turn reinforcing the interiority of the individual and, in some cases, requiring HIV test subjects to reveal intimate truths about themselves. In recent years, HIV tests and the confessions they bring forth have become the central means of evaluating efficacy for pharmaceutical interventions. In clinical trials evaluating novel HIV prevention technologies, as participants confess their inner truths, they support the commercialisation of pre-exposure prophylaxis (PrEP) therapies. Indeed, this new formation of diagnostic techniques—both biological and verbal—made clinical research for PrEP possible by defining the study population and providing evidence of pharmaceutical efficacy. Conversely, PrEP trials offered a new opportunity for the use of HIV tests. Whereas for the past three decades HIV testing has been vital for researchers to understand the path of transmission and the way subjects reveal truths about themselves, within PrEP trials, testing also became integral to the production of evidence for pharmaceutical efficacy.

To more fully comprehend the role of diagnostics in responses to global pandemics, we must attend to specific contexts of use (including public health surveillance programmes and clinical research for drug development) and related transformations in the ethics and practices of human subjectivity. Following the trajectories of diagnostic technologies across various contexts of use and in relation to the ongoing constitution of at-risk subjectivities offers new vantage points from which to examine the processes through which clinical data is produced and provides insights into the production of evidence in clinical research for drug development. Whereas others have argued that US health

researchers must attend to the conditions of clinical trial participation as a form of labour to unearth the inequities that make drug development possible (Petryna 2009; Cooper and Waldby 2014), it is equally important for anthropological analyses to examine the constitution of at-risk subjectivities and the role of subjective practices in the production of the evidence required to commercialise new therapies. Thus, I argue that confessions should be understood as a form of labour that enables the development of drug products and facilitates the growth of markets.

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