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Que(e)rying artificial intelligence use for infectious disease surveillance: The need for a reparative algorithmic praxis

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Abstract

The increasing likelihood of pandemics highlights the need for superior tools at our disposal. By robustly and efficiently analyzing vast datasets, artificial intelligence (AI) has the potential to help decision-makers better respond to, manage, and even avert infectious disease outbreaks. However, these systems could also stigmatize, discriminate, exclude, exploit, and/or otherwise oppress vulnerable populations. In doing so, they could amplify allocative and representational harms. Given the possible far-reaching consequences, critical ethical reflection and oversight are essential. Such reflection would be incomplete without considering the impacts on queer people. From HIV/AIDS to COVID-19, outbreaks have disproportionately affected sexual and gender minorities (SGMs), reflecting a long history of structural oppression and injustices. AI could further exacerbate inequalities—like anti-queer bias—particularly amid the omission of marginalized and minoritized perspectives from algorithmic fairness efforts. Adopting an Intersectional, reparative approach, this paper que(e)ries the use of AI for infectious disease surveillance purposes. Placing this technology within patterns of power, privilege, marginalization, and disadvantage, it interrogates how to achieve algorithmic justice for SGMs. It proposes concrete steps towards a reparative algorithmic praxis, including: (1) exploring how these systems reproduce inequalities, (2) centering sexual and gender diversity to disrupt problematic epistemic positions, and (3) combating opacity through participatory governance mechanisms. This work is necessary to understand how AI systems reproduce major health disparities and hold them accountable. By contemplating how to begin redressing harms, it offers a starting point for further deliberation and action towards inclusive, justice-oriented algorithmic systems in practice. I anticipate these lessons being deeply transferrable across contexts.

Keywords

Infectious diseases, artificial intelligence, algorithmic bias, algorithmic reparations, queer theory, Intersectionality

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The increasing likelihood of pandemics highlights our need for superior tools to combat them. By swiftly analyzing vast datasets, artificial intelligence (AI) can empower decision-makers to better respond to, manage, and even avert infectious disease outbreaks (Wong et al., 2019). For instance, AI technology—such as natural language processing, machine learning (ML), and location monitoring—can be used to pinpoint where outbreaks are likely to occur and anticipate the pattern of disease spread. Optum Flu

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Nowcasts and BlueDot are two noted models. Both use ML to find hidden patterns within masses of disease indicator data (internet search queries, social media posts, patient records, academic research, national syndromic surveillance systems). These predictions can be hugely beneficial during a public health crisis, influencing vital response and preparedness measures. Algorithmic systems may, therefore, shape important decisions such as how and where to allocate scarce resources, or what proactive containment and prevention strategies to adopt. The expectation is that AI will drive selection of more effective and informed measures that reduce injury, disruption, and loss of human life.

However, AI technologies pose risks. Algorithmic bias based on various characteristics (gender, sexual orientation, race/ethnicity, class, disability) has been well-documented. Optum received attention for racial bias in one of their other algorithms, which deployed for years in hospitals across the United States impacted millions of patients before detection (Obermeyer et al., 2019). AI fairness efforts attempting to address such biases have fallen short, in part due to algorithmic idealism, or the erroneous assumption of a meritocratic society denoted by historical equal treatment (Davis et al., 2021; So et al., 2022). With the potential to (re)entrench unequal distributions and hierarchies, these algorithmic systems are morally significant. This includes the processes by which these systems assign risk to individuals and groups. Such risk classifications may further stigmatize, discriminate, exclude, exploit, and/or otherwise oppress vulnerable populations. For example, AI pandemic surveillance systems could disproportionately flag LGBTQIA + spaces like gay bars or community centers as high-risk, leading to targeted closures, restrictions, or increased policing of these venues. Meanwhile, AI-powered contact tracing could more easily expose queer networks and enable outing. These tools could thereby amplify allocative and representational harms. Given the possible far-reaching and substantial consequences of these harms, critical ethical reflection and oversight are essential.

Such reflection is incomplete without an analysis of the effects of these algorithmic systems on queer people. From HIV/AIDS to COVID-19 to mpox, outbreaks have disproportionately affected sexual and gender minorities (SGMs). This reflects a long history of structural oppression and injustices experienced by queer individuals (Gil et al., 2021). AI/algorithmic systems could further exacerbate inequalities—such as anti-queer bias—particularly amid inadequate legal protections and the omission of marginalized and minoritized perspectives from algorithmic fairness efforts (Albert and Delano, 2021; Davis et al., 2021; Dhar, 2021; Tomasev et al., 2021). This is especially concerning when we consider the already wide adoption of commercial risk-prediction algorithms in the health sector (see Obermeyer et al., 2019).

Drawing from queer and critical race theory, this work adopts an Intersectional, reparative approach (see Davis et al., 2021) to que(e)rying the use of AI for infectious disease surveillance purposes. Placing this technology within patterns of power, privilege, marginalization, and disadvantage, it interrogates how we can achieve algorithmic justice for SGMs in the face of these emerging tools. Such inquiry is necessary to not only understand how algorithmic systems reproduce major health disparities but hold them accountable. This research contemplates how we can begin the process of redressing harms and the vital role a reparative algorithmic praxis can play. I envision this piece as a starting point and hope it acts as an impetus for further deliberation and action.

The importance of a queer, Intersectional orientation: A call to action

Shaped by the "interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors" (World Health Organization [WHO], 2006), human sexuality is complex, diverse, fluid, and polymorphous (Oosterhoff and Sweetman, 2018). Gender identity is similarly constructed with different social and cultural values producing varying gender norms. These constructs (sexuality, gender, race/ethnicity, class, disability) are deeply relevant when we examine why viruses decimate certain communities and not others. Focusing on the HIV/AIDS and COVID-19 pandemics, Thrasher (2022) elucidates this "fraught relationship between privilege and survival."

It is well-established that SGMs experience a disproportionate burden of physical and psychosocial health disparities, including higher rates of violence, mental health issues, substance misuse/abuse, communicable diseases (STIs, tuberculous, hepatitis), and non-communicable diseases (cancer, diabetes, cardiovascular disease) (James et al., 2016; Pillay et al., 2022; Zeeman et al., 2019). The reasons for this are multifold and comprise minority stress, severe economic hardship and instability, insufficient training amongst healthcare professionals as to how to best meet the needs of queer patients, and other consequences of prejudice, stigmatization, and discrimination (Tomasev et al., 2021). Bisexual women, for example, have significantly higher prevalence of cervical cancer compared to heterosexual women (41.2% versus 14.0%), theorized partially due to a lack of adherence to screening and HPV vaccination guidelines (Quinn et al., 2015). Systemic barriers to accessing quality, appropriate (e.g., gender-affirming) care further compound these issues. Amongst transgender individuals, 33.0% reported negative experiences with healthcare providers related to their gender identity, 23.0% avoided necessary care due to fears of mistreatment, and 33.0% did not seek care because they could not afford it (James et al., 2016).

This reality emphasizes the importance of employing algorithms that are grounded in socio-historical contexts,

particularly as these systems become increasingly responsible for healthcare decision-making and allocation in societies with structural inequalities. Yet many algorithmic fairness efforts lack this crucial context. Poor diversity in relevant spaces has contributed to the predominance of algorithmic idealism. SGMs are routinely underrepresented in global health and AI—both of which operate from epistemological positions of hetero-cis-normativity (Pillay et al., 2022; see Tomasev et al., 2021). Albert and Delano (2021) explore this convergence as they discuss how personal health tech utilizing AI encodes binary perceptions of sex/gender.

Consequently, algorithmic systems can perform less accurately for and harm SGMs. Commercial facial analysis technologies misclassified transgender individuals up to 38.3% of the time compared to 0–4.9% for cisgender individuals, while the accuracy rate for non-binary genders was analytically calculated as 0% since these services only return binary gender labels (Scheuerman et al., 2019). Such misclassification and erasure can result in discrimination, privacy violations, psychological distress, reinforcement of binary gender norms, exacerbation of inequalities, and chilling effects on freedom of expression. Queer theory offers much-needed insights into how (a) hetero-cis-normativity permeates throughout society (see LGBTQ Nation, 2021) and reifies unequal power dynamics and (b) AI-powered technology risks further marginalizing SGMs by entrenching these societal assumptions and systems of privilege.

In addition to a dearth of queer voices in AI design, development, deployment, and research, there is insufficient data documenting the queer experience. This severely curtails our ability to grasp—let alone address—the impact of algorithmic systems on those identifying as queer. The challenge partly arises from the fact that sexual and gender identity are "prototypical instances of unobserved characteristics, which are frequently missing, unknown, or fundamentally unmeasurable" and current algorithmic fairness activities have largely been designed with observed characteristics in mind (Tomasev et al., 2021). This significantly limits their suitability here and further accentuates the need for alternative (reparative) methods. When we fail to question the impacts of socio-historical constructs, we accept inequalities as naturally occurring and enable algorithmic systems to reproduce, amplify, and essentialize them and their associated harms.

The interplay between various constructs also underscores the need to adopt a praxis rooted in theories of Intersectionality that considers how overlapping aspects of identity (race/ethnicity, gender, class, disability, religion, sexual orientation) influences lived experiences, particularly as they relate to discrimination and marginalization (Davis et al., 2021). Amongst SGMs, the impacts of a virus may be unevenly felt. In the United States, while the lifetime risk of acquiring HIV is currently one in six for all gay and bisexual men, that risk increases for Black (one in two) and Latinx (one in four) gay and bisexual men (Rodriguez, 2020). Despite these differences in health outcomes, however, when included, queer individuals are frequently (and indiscriminately) grouped together (see Pillay et al., 2022). Moreover, the Western hetero-cis-normative categorizations that are utilized—such as those promoting gender binarism—are extensions of colonial, capitalist power (see Mohamed et al., 2020). Given how as an apparatus of coloniality, public health (encompassing epidemiological reasoning) perpetuates global inequities (see Richardson, 2021), a decolonial approach is likewise important.

These hetero-cis-normative, colonial, and capitalist positions and priorities pervade infectious disease surveillance technologies, which are predicated on non-representational data that does not "properly engage with gender and sexual minorities" (Gitzen and Chun, 2021). This and biased proxies may result in inaccurate risk scores being assigned to queer populations with detrimental consequences—like the adoption of more stringent and unnecessary preventative measures (curfews, quarantines, stay-at-home orders) or the inadequate provision of life-saving resources (vaccines, testing kits, PPE, ventilators, drug treatments). The benefits of these systems could subsequently be substantially less for SGMs relative to their cisgendered heterosexual peers (Tomasev et al., 2021). Furthermore, these tools can increase risks of ostracism, oppression, and violence for SGMs, especially in environments where their security and wellbeing are not guaranteed. In South Korea where queerness is highly stigmatized, an extensive surveillance system combined with unpreceded government sharing of personal information resulted in discrimination as queer individuals were identified, targeted, and blamed for rises in COVID-19 cases (Gitzen and Chun, 2021).

Reparative algorithmic praxis: A way forward

As Tomasev et al. (2021) encapsulate, "given the historical oppression and contemporary challenges faced by queer communities, there is a substantial risk that artificial intelligence systems will be designed and deployed unfairly for queer individuals." Since these solutions speak the language of science and technology, however, they lend credibility and perceived impartiality to the systems in which they are embedded. But as multiple scholars have stressed, technology is not neutral. Moreover, machine learning has a long history of intensifying and perpetuating major structural and historical inequalities—which fair ML practices have failed to acknowledge and address (Davis et al., 2021; Hanna et al., 2020; So et al., 2022; Tomasev et al., 2021). By default, algorithms are manifestations of a deeply unjust society. Guided by meritocratic misconceptions and focused on erasing demographic differences to

achieve equal performance, traditional fairness models are inherently flawed and will always fall short when tasked with systemic redress (Davis et al., 2021). Which leaves us with the question: how then do we action SGM affirmative algorithms in practice?

In "nam[ing], unmask[ing], and undo[ing] allocative and representational harms as they materialize in sociotechnical form" (Davis et al., 2021), algorithmic reparations offer a promising way forward. As this discussion until now illustrates, it is imperative for us to go beyond technical performance and consider how algorithms can (a) shift power and (b) fit within broader historical and societal patterns of oppression, privilege, marginalization, and disadvantage (see Davis et al., 2021; Johnson, 2021; Kalluri, 2020). A reparative approach would do the essential work of contextualizing these algorithms and assist us in leveraging biases in pursuit of social equity (Davis et al., 2021)—including re-orienting algorithmic systems from predicting risks to formulating intervention policies (So et al., 2022). Moreover, it would encourage us to continue drawing from additional approaches (Intersectionality, decoloniality) as we go about these activities.

As for concrete steps to take, other works afford some direction. First, while a subset of the literature investigates allocative and representational harms in ML more broadly (see Davis et al., 2021), there are limited explorations of how this usage of algorithmic systems may exhibit, reproduce, and/or augment inequalities. Better understanding these processes and how these systems fit within hierarchies of power and privilege is key. We must consistently ask who these systems serve. Let us envision an algorithmic system whose purpose is identifying areas of elevated disease incidence or transmission risk, known as "hotspots"—a crucial component of infection prevention and control strategies. A reparative approach could scrutinize how the system inaccurately assesses risk—such as by employing non-representative datasets and proxies that encode anti-queer biases and fail to account for structural inequities–and disproportionately flags LGBTQIA + spaces. We would delve into the harm caused as safety is undermined and individuals targeted and ostracized. Further contextualizing may involve analyzing the sociohistorical factors contributing to data gaps, engaging affected populations to understand lived experiences, and exposing how such assessments replicate broader patterns of marginalization. Reorientation would then comprise redirecting these algorithmic systems towards promoting interventions aimed at the disproportionate burden of health disparities experienced by queer people instead.

Examining the various barriers (institutional, legal, social, political) to actioning reparative algorithms in this specific context would also be invaluable. Addressing these necessitates not only additional scholarship but transdisciplinary collaborations (see Davis et al., 2021) between academic researchers (especially, queer- and race-conscious social scientists and ethicists), public health practitioners, AI developers, policymakers, and SGM community stakeholders. In practice, these could take the form of (a) workshops incorporating queer theory into algorithm design, (b) policy roundtables debating the societal impacts and potential harms of various surveillance approaches, (c) algorithmic pilot testing with ongoing feedback from affected communities, and (d) the co-creation of reparative data collection methods capable of tackling socio-historical power structures (see Davis et al., 2021; Hanna et al., 2020; Jo and Gebru, 2020) and the challenges posed by complex Intersectional identities and unmeasurable characteristics like sexual orientation. Various works have highlighted the formative expertise archival and library sciences can proffer as we go about this last task (see Davis et al., 2021; Jo and Gebru, 2020). These efforts also draw on the formative knowledge and innovative perspectives provided by queer lived experiences–including unique insights into subverting harmful data logics and reimagining inclusive algorithmic systems. This is exemplified by queer communities' rich histories of creative resistance, obfuscation, anti-surveillance, and counter-conduct tactics, such as using drag makeup to confound facial recognition algorithms (Kornstein, 2021).

Second, disrupting prevailing epistemic positions and power arrangements and identifying problematic technology requires centering sexual and gender diversity and complexity. Contextualized by a specific history, geography, language, and culture, Western categorizations (e.g., homosexuality) may not only be unsuitable in other cultural settings but censor this diversity and complexity–especially if the systems of power and inequalities differ from the social settings in which such language was coined (Oosterhoff and Sweetman, 2018; Young and Meyer, 2005). Such terminology can not only undermine local self-determined identities but obscure social dimensions of sexuality and sexual behavior that are critical to understanding the unique health needs of affected populations (see Racine, 2023). Moving forward requires providing inclusive support for a range of sexual orientations and genders, including utilizing local terms which articulate these different histories, power relations, and social hierarchies. Again, collaboration is paramount as we continue to empower diverse voices, especially those most impacted by AI technologies (see Kalluri, 2020) and via methods such as distributed AI power tactics (see Davis et al., 2021; Mohamed et al., 2020). Such elevation is an indispensable component of reparations and would hugely benefit from an Intersectional orientation.

Third, AI-enabled health systems and the ways in which they shape decision-making are often opaque to human understanding. The proprietary nature of large-scale algorithms–including training data, objective function, and prediction methodology–can greatly hinder independent auditing, timely detection of bias, and efforts at redress (Obermeyer et al., 2019). Combatting opacity requires

developing participatory governance mechanisms that meaningfully encompass marginalized and minoritized perspectives. Algorithmic impact assessments–especially when made public–are one oversight tool that can support affected communities in evaluating claims about algorithmic systems and alignment with values such as equity, justice, bias, accountability, and transparency. The Government of Canada's Gender-Based Analysis Plus framework illustrates how to integrate Intersectionality into such evaluations. These instruments are crucial to determining not only the appropriateness of algorithmic systems, but how harms can be remedied or whether a system should be dismantled. Furthermore, accountability mechanisms can help proactively establish standards and reparative processes for addressing the large-scale societal impacts of these systems. The rapid emergence and scaling of AI-powered pandemic surveillance tools during COVID-19 highlights the urgent need for proactive measures.

While this commentary focuses on SGMs and infectious disease surveillance, its lessons are deeply transferrable across identity characteristics, use cases, and sectors. I hope this work underscores not only the importance of adopting an Intersectional, reparative praxis for all AI-powered tools, but the vital guidance que(e)rying algorithmic design, development, and deployment can offer as we action inclusive, justice-oriented systems in practice.

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