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TARGET ARTICLE



Structural Racism in the COVID-19 Pandemic: Moving Forward

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ABSTRACT

The COVID-19 pandemic has taken a substantial human, social and economic toll globally, but its impact on Black/African Americans, Latinx, and American Indian/Alaska Native communities in the U.S. is unconscionable. As the U.S. continues to combat the current COVID-19 cycle and prepares for future pandemics, it will be critical to learn from and rectify past and contemporary wrongs. Drawing on experiences in genomic research and intersecting areas in medical ethics, health disparities, and human rights, this article considers three key COVID-19-related issues: research to identify remedies; testing, contact tracing and surveillance; and lingering health needs and disability. It provides a pathway for the future: community engagement to develop culturally-sensitive responses to the myriad genomic/bioethical dilemmas that arise, and the establishment of a Truth and Reconciliation Commission to transition the country from its contemporary state of segregation in healthcare and health outcomes into an equitable and prosperous society for all.

KEYWORDS



Community engagement; COVID-19; genomic research; structural racism; truth and reconciliation commission

INTRODUCTION

Pandemics first and foremost hit those who are most vulnerable, and the COVID-19 pandemic is no different. Although the infection rate in the nation's poorest neighborhoods is twice as it is in the wealthiest neighborhoods (Hauck et al. 2020), it is the racial and ethnic disparities that are paramount. Emerging data show that Blacks/African Americans (AAs), Latinxs and American Indians/Alaska Natives (AI/ANs) are far more likely than non-Latinx Whites to be sickened and to die from COVID-19, and the rates are staggering (CDC 2020c). The age-adjusted death toll among Blacks/AAs and Latinxs is on average 5.6 and 4.3 times higher, respectively, than that for Whites (Ford, Reber and Reeves 2020). Among AI/ANs, COVID-19 incidents (Hatcher et al. 2020) and hospitalization (CDC 2020d) are 3.5 and 5.7 times higher, respectively, than among Whites; the estimated mortality rate is far higher than their relative weighted distribution in the U.S. population (National Indian Health Board 2020a; NCAI 2020). And, the real numbers are yet likely to be higher. These data do not include comprehensive information from uncontested hotspots for COVID-19 deaths, e.g., nursing homes, residential

facilities, jails/prisons and other closed employment settings (e.g., meat industry) (Chidambaram 2020) that are often overrepresented by Latinxs, Blacks/AAs and AI/ANs (Cunneen and Tauri 2019; Dyal et al. 2020; Molteni 2020; Waltenburg et al. 2020). These data do not include individuals who were unable to be tested, declined to seek assistance at acute care facilities despite showing symptoms, and/or died at home without a medical cause being clearly determined. These data also need to be considered given what the CDC described as "excessive absence of data among AI/ANs," including lack of reporting and racial and ethnic misclassification of AI/AN that result in underestimates of mortality rates among this population (Hatcher et al. 2020).

This disproportionately high impact on marginalized racial and ethnic minorities *was* expected. Although the U.S.'s reaction during the 2005 Hurricane Katrina had exposed the underlying structural effects of racial and class differences (Brunkard, Namulanda and Ratard 2008), studies show that systemic issues have not been rectified, and that emergency responses during and recovery after natural disasters remain negatively associated with racial and ethnic minority status

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(Davidson et al. 2013; Willison et al. 2019). The COVID-19 pandemic is further notable because, unlike previous emergencies that revolved around disasters such as fires, hurricane, and acts of terrorism, it directly intersects with the U.S.'s problematic health-care system.

That the U.S.'s privatized healthcare system is prone to create and exacerbate health inequities is well established. Studies show that racial and ethnic minorities, especially Blacks/AAs and AI/ANs, experience more barriers than non-Latinx Whites to routine, preventative and high-quality care (National Academies of Sciences Engineering and Medicine 2017; National Indian Health Board 2020b). They are less likely to have a primary health provider and more likely to have poorer health outcomes, including chronic, unmanaged, medical conditions such as hypertension, obesity, diabetes, cardiac diseases, and asthma (CDC 2017, 2019a–c, 2020a; National Academies of Sciences Engineering and Medicine 2017; Tai et al. 2020). Significantly, such conditions are associated with increased COVID-19 morbidity and mortality (Garg et al. 2020; Halpin et al. 2020). A further compounding factor is the disproportionately high prevalence of disabilities among Black/AA, Latinx, and AI/ANs communities (Yee et al. 2018), a demographic that is not currently consistently reported or provided (Sabatello et al. 2020). Although disability itself cannot be equated with poor health, people with disabilities comprise the largest health disparities group in the U.S. (Krahn, Walker and Correa-De-Araujo 2015). They are 2–3 times more likely than non-disabled peers to report not having access to needed treatment due to cost, twice as likely to report unmet mental health needs, and less likely to have a range of preventative services (Hathaway 2020; Yee et al. 2018). People with dual minority statuses (disability and racial and ethnic marginalization) thus often have even poorer health outcomes, including higher rates of chronic medical conditions than their non-disabled peers (Yee et al. 2018).

The COVID-19 pandemic has brought these profound health disparities to the forefront. Uninsured and underinsured individuals—who are mostly from lower socio-economic communities and disproportionately higher among racial and ethnic minorities (Sohn 2017)—were initially denied testing, a first step in stopping a pandemic. Once COVID-19 testing began to be provided for free, more testing locations were available in wealthier neighborhoods (Wellington 2020), notwithstanding the higher need in poor neighborhoods of predominantly racial and ethnic

minorities (Lieberman-Cribbin et al. 2020) and AI/ANs tribal communities for whom the distribution of testing kits has been largely absent (Doshi et al. 2020). Beyond testing, the cost of COVID-19-related hospitalization is prohibitive for many individuals, especially poor racial and ethnic minorities (KFF 2018). With estimated costs of \$1,400–\$2,000 for Medicare patients (Neuman, Damico, and Cubanski 2020) and \$13,000–\$40,000 for uninsured patients (Levitt, Schwartz, and Lopez 2020), depending on length of hospitalization, such medical bills exceed the annual wages of some full-time employees (e.g., the median wage for Black/AA women is \$38,036 (National Partnership for Women and Families 2020)). By the time the Coronavirus Aid, Relief, and Economic Security (CARES) Act was passed to reimburse hospitals for treating uninsured COVID-19 patients (a privilege not yet materialized among AI/AN tribes (Doshi et al. 2020; Dorn, Cooney, and Sabin 2020)), the virus had spread, wreaking havoc in these communities.

Major disasters reveal both strengths and weaknesses in our community's ability to respond, recover, and provide an opportunity for improvement. As the U.S. continues the effort to abate its COVID-19 infection rate and prepares for future pandemics, it will be critical that we take note of mistakes and lessons learned. In this regard, although existing data on health disparities are not new, recounting them underscores the magnitude of neglect and cements the experiences of racial and ethnic minorities in the social memory (Avruch 2010). Such an evaluation also must be undertaken within the broader societal context in the U.S.: the killing of George Floyd during the pandemic, followed by nationwide protests over police brutality and public demands for social justice. This article considers key issues in the response to the COVID-19 pandemic that are likely to arise, drawing on experiences in genomic research and intersecting areas in medical ethics, public health, and human rights to inform the next steps.

Our starting point is that race and ethnicity are not biological, but rather sociopolitical constructs (Morning, 2011; Roberts 2012). Studies indicate that the genetic similarity among all human beings is 99%, and that the genetic diversity *within* (rather than between) racial and ethnic groups is paramount (Rosenberg et al. 2002; Witherspoon et al. 2007). Simply stated: there is no genetic basis for racial and ethnic categories. Although this scientific truth should have created a sociobiological solidarity—i.e., alliance of *all* human beings, regardless of racial and ethnic

group identification—misunderstanding or distorted use of genomics have reinforced socially abhorrent beliefs such as racism, sexism, and ableism (Condit 2019; Heine et al. 2017; Isler et al. 2013; Panofsky and Donovan 2019; Sabatello and Juengst 2019). Moreover, genetic research itself can reinforce the racist ideas rooted in race science (Saini 2019). Its use of racial and ethnic categories as a-priori risk factors in genomic research have given rise to assumptions that racial health disparities are the result of race-based genetic differences or race-neutral economic difference rather than social inequality (Roberts 2012). This article is predicated on the belief that the combination of genomic/scientific-based and societal-based forces that impact contemporary discourses in genomics also are the underpinning elements affecting the reasons, outcomes, and future prospects for the COVID-19 pandemic. We focus on three key arenas that are most cardinal to consider—i.e., research to identify remedies; COVID-19 testing, contact tracing and surveillance; and lingering health needs and long-term disability among COVID-19 patients and beyond—and provide a pathway for the future.

RESEARCH TO IDENTIFY REMEDIES, RESEARCH PARTICIPATION AND EQUITABLE ACCESS TO BENEFITS

As the causalities from the pandemic unfold, and with prospects that COVID-19 will resurge seasonally, the urgency in identifying treatments and vaccines cannot be overstated. Numerous clinical trials have already been launched to promote these goals (NIH 2020). The heterogeneity of COVID-19 patients' symptoms and mortality rates similarly raise growing interest in finding biological and environmental factors that impact responses to COVID-19. Established and newly created biobanks (Morelle 2020; Ross 2020) have thus begun inviting COVID-19 patients to provide samples and clinical data for research, from convalescent plasma to explore possible treatments for severe patients (Duan et al. 2020) to genetic sequencing to identify viral lineages and an individual's increased vulnerability to COVID-19 (Forster et al., 2020).

The collection and use of data from COVID-19 patients is promising for possible prevention, treatments, and therapeutic options for COVID-19 patients. The pool of potential COVID-19 research participants is large and may allow for a nuanced understanding of the disease and its' interaction with underlying conditions. Although the motivations for

research participation may vary, they often include personal, familial and societal-level benefits, such as desire to benefit others and help advance scientific/medical research (Halbert et al. 2016; Kaufman et al. 2008; Sanderson et al. 2017). Given the urgency and dire consequences of COVID-19, there is hope that enrollment across racial and ethnic groups will be high, unlike other biomedical studies that have long suffered from underrepresentation of racial and ethnic minorities (Branson, Davis and Butler 2007; Popejoy and Fullerton 2016).

Although studies have found that support in research participation for specific diseases is high (Coubier et al. 2019; Kaplan et al. 2015), it is yet to be seen whether the hope for diverse COVID-19 biobanks will materialize. With the disproportionate effects of the pandemic on racial and ethnic minorities, it is conceivable that members of such communities will choose to further disengage from biomedical research and the healthcare system that has failed them. Moreover, studies indicate that racial and ethnic minorities express concerns about participation in genomic research. The reasons include fear of discrimination, negative personal and community-level experiences in healthcare and research (including e.g., the Tuskegee Syphilis Study and misuse of research data from the Havasupai and Nuuchah Nulth tribes), and overall distrust in healthcare providers, the healthcare system, and researchers who are unknown to them (Branson, Davis and Butler 2007; Claw et al. 2018; Corbie-Smith, Thomas, Williams, and Moody-Ayers 1999; Kraft et al. 2018; Passmore et al. 2019; Sabatello et al. 2020; Ulrich et al. 2013).

Although it is plausible that the pandemic's magnitude will dwarf these worries and generate a sense of "common morality" in favor of research participation, the opportunities that arise from research require caution in enrollment of racial and ethnic minorities. The open-ended nature of COVID-19 studies, especially the genomic component thereof, may not be immediately realized by COVID-19 patients and their family members. The implications of limited understanding on research participation has been debated. Some scholars hold that the provision of easy-to-understand information is sufficient, while others suggest that substantive comprehension of key issues is necessary for enrollment into research (Appelbaum 2019; Beskow and Weinfurt 2019). Regardless, assurance of understanding of the genomic component in COVID-19 biobanks will be critical for efforts to rebuild trust. Even as obtaining informed consent may be more complicated due to social distancing and time

limitations, researchers' transparency, culturally-sensitive practices for engagement (Otado et al. 2015) and measures such as use of telemedicine tools are needed to assure that COVID-19 patients (and their families) are properly informed about the study's goals and benefits, including whether genomic sequencing will be used, how results will be returned to them, and the types of research in which patients' data may be used in the future.

Principles of fairness and distributive justice should inform the work of biobanks, researchers and funders. In the U.S., these principles have often focused on the expectation that the opportunities and burdens of research participation be shared fairly among the general population, while fair and equitable access to the benefits of scientific knowledge has lagged behind. Reporting criteria in clinical studies focus on racial and ethnic inclusion but not on reciprocity and justice in outcomes. This is the case even as public resources including societal participation (e.g., recruitment through collaborations with academic institutions) and financial investment (e.g., NIH-funded collaborations) are regularly utilized in such research efforts. Pharmaceutical companies in the U.S. have been permitted to charge exorbitant prices for drugs and treatments (Deangelis 2016), even as this practice has resulted in rapid rises in health insurance premiums and out-of-pocket spending that are unaffordable to many (Haker 2020). And, the unfairness of poor and uninsured research participants having no access to post-trial products is tolerated and sustained on the grounds that it "stems from the background circumstances, not from the trial, and therefore does not translate into exploitation" (Pace, Miller and Danis 2003, S123).

The COVID-19 pandemic forces us to refocus on equitable access to the benefits of scientific knowledge, though how to make it work raises challenges. Conceptually, the normative expectation of "fair and equitable benefit-sharing" clarifies neither what "fair" nor "equitable" means, and extrapolating substantive meaning is inherently value-laden. Processes to ensure equitable access are also vulnerable to knowledge and power imbalances between the haves and the have-nots (De Jonge 2011). Consider, e.g., equitable justice in research collaborations between low-/mid-income countries and researchers (i.e., universities and biotech companies) in high-income countries. To date, this has been a prime area for discussions on benefit-sharing (Millum 2012) and in some cases, it has translated into local capacity building and data-sharing of otherwise inaccessible populations (e.g., H3Africa and

Gates Foundation's Data Science Nigeria). Although ethical guidelines in global research highlight the importance of benefit-sharing (UNESCO 1997; Dauda and Dierickx 2013), access of research participants to the research products (so-called "desert" or compensatory justice rationale (Simm 2007)) is commonly left to the researchers' discretion (through, e.g., "compassionate use" programs). In contrast, the distribution of research products to local populations (so-called solidarity-based justice (Simm 2007)) is unaddressed. Benefit-sharing raises other issues about individual and collective ownership of biosamples used in research that are culturally-based. Whereas in European countries human material in biobank databases frequently remain in the public domain, even if they are privately owned, the regulatory system in the U.S. transfers these public goods to, and is designed to protect the interests of, for-profit entities (De Jonge 2011; Jefferson 2015).

Addressing these challenges and changing long-standing norms may be difficult, but the COVID-19 pandemic must be a turning point. The underlying rationales for benefit-sharing in global research hold at even a greater force in the national response to this pandemic. Consider, e.g., the assumption in global research that the development of local expertise would facilitate health improvements of the local population. Undoubtedly, this tradeoff could be applicable to racial and ethnic minorities in the U.S.: culturally responsive research that augments local resources, expertise and knowledge could contribute to the alleviation of health disparities. But real and lasting changes at the local (and national) level are unlikely to occur without addressing the root causes for the disparities. In the U.S., these include systemic inequalities in the distribution of resources to communities of color, and more generally, the presence of an exclusionary system that builds on the cumulative inequality of Black/AAs and other marginalized racial and ethnic minorities in society and which results in dire health disparities (Bailey et al. 2017; Fleischman and Franklin 2017; National Indian Health Board 2020b; Williams, Lawrence, and Davis 2019).

Allowing private entities to make their usual hefty profits only adds insult to injury; it also stands in contrast to existing ethical guidelines for human subject research, such as protecting disadvantaged populations from exploitation and compensating them for their contributions in research (Dauda and Dierickx 2013; Millum 2012). With Blacks/AAs, Latinxs and AI/ANs bearing the brunt of the pandemic's burden, more likely by the sheer volume of severe COVID-19

patients from these communities to be involved in experimental, unproven and risky studies to identify cures (Rome and Avorn 2020), and for their biosamples including invaluable convalescent plasma to be used in COVID-19-related research, the reliance on patients' "common morality" to contribute to these activities must be accompanied by a reciprocal "common morality" to a genuine benefit-sharing agreement.

As a start, arrangements should require a public commitment by all research stakeholders—i.e., research institutions, private/pharmaceutical companies and funders—that no one will be left behind. Access to COVID-19 scientific benefits needs to be conceptualized as an inherent right, grounded in human dignity, equality, and our moral obligation to improve the fate of the worst off. Although the U.S. has been averse to such understandings in the past, the nature, magnitude and global ramifications of the COVID-19 pandemic justify a different approach. While a comprehensive list of possible approaches is beyond the scope of this article, possible measures to facilitate this shift include: free testing, a moratorium to prohibit patenting of COVID-19 products, stringent capping of the prices of COVID-19 products to ensure widespread access, and restrictions (including University-based regulations) to assure that data sharing is conducted only with entities that are committed to genuine benefit-sharing. Such measures promote sociobiological solidarity and support key underlying rationales for data sharing: leveraging publicly funded research to serve the public good and advancing scientific knowledge and application to human health (Borgman 2012). It should thus be within the responsibility of local and national regulatory bodies to clarify (or revise) data-sharing policies to assure compliance with these values.

The use of patients' samples for viral lineage analyses to identify pathogen genomic mutations and sources of contagious diseases may also raise concerns. Such analyses harness epidemiological knowledge and affordable genomic sequencing technologies to promote public health endeavors to surveil, diagnose, and provide real-time tracking of emerging infectious diseases (Gardy and Loman 2018). However, the use of pathogen genomics may result in unintended societal outcomes that are especially heightened for marginalized populations. These include blaming communities for the spread of diseases, stigmatization and increased xenophobia toward marginalized groups, while socioeconomic and political implications are ignored (Juengst 2019). Signs of this dynamic already

have begun to emerge in the COVID-19 pandemic, with a sharp increase in the reporting of incidents against Asian communities (NYC Commission on Human Rights 2020), notwithstanding research indicating that the source of New York City's pandemic, e.g., has been primarily from European and U.S. travels (Gonzalez-Reiche et al. 2020). Likewise, there is a concern that COVID-19 lineage analysis that locates hotspots of infection in Black/AA, Latinx and AI/AN communities will lead to the misattribution of the high morbidity and mortality rates among members of these communities to increased biological susceptibility to COVID-19 rather than to the systemic disparities in accessing healthcare and other basic needs such as clean water (a major issue among AI/AN communities (Rodriguez-Lonebear et al. 2020)). Similar racist theories of biological inferiority of Blacks/AAs were prevalent in the 1918 influenza pandemic (Gamble 2010), and misuse of genomic analysis may revive such claims. Pathogen genomic efforts should consider the possible impacts of such information on racial and ethnic minorities and ensure that messaging about the virus upholds the scientific responsibility of addressing, not exacerbating, social harms. Measures to this effect may include researchers' respectful interaction and ongoing collaboration with communities to plan appropriate mitigation measures and to monitor discrimination and assure that their public messages are accurate and scientifically-based (Center for Health Security 2020). Ultimately, there is a need for researchers to a-priori think about *why* race is used as a research variable or diagnostic tool, and whether the reasons for such use are well-thought and grounded in scientific rationales rather than stereotypes (Saini 2020).

COVID-19 TESTING, CONTACT TRACING AND SURVEILLANCE

COVID-19 testing, contact tracing and surveillance of risky behaviors among individuals who tested positive or are asymptomatic are critical for efforts to identify new hotspots and prevent the spread of infection in the future.

To date, the discussion has largely focused on testing: the failure of early testing to warn off the pandemic, the current shortage in testing kits, and the risk of (especially) false negative results that would thwart early intervention and prevention efforts (West, Montori and Sampathkumar 2020). Suggestions to test the public for COVID-19 antibodies and to issue "immunity-based licenses/passports"

as considered in several countries, including the U.S. have raised questions about the scientific validity, accuracy and predictive power of such testing (Phelan 2020). These important testing-related issues do not seem to exceed traditional concerns in medicine: they raise the question of access, stockpiling and growing scientific knowledge of COVID-19. However, contact tracing and especially surveillance of COVID-19-positive individuals in the era of digital technologies raise ethical and practical concerns.

Contact tracing—i.e., interviewing patients and proxies to identify individuals exposed to the health risk—is a pillar of communicable disease control in public health and has long been used to effectively control virus-related outbreaks such as Ebola, TB and Zika (Saurabh and Prateek 2017). Although a time and labor consuming endeavor, it is believed to be indispensable for efforts to subsume infectious diseases, including COVID-19 (Hellewell et al. 2020; Korea Centers for Disease Control and Prevention 2020a). Concurrently, the need for a rapid response, concerns about patient or proxy's recall bias, and urgency in the containment of the spread of COVID-19 have led to increased harnessing of the power of technologies. Countries around the world have taken various approaches to digital tracking, including voluntary apps and mandatory surveillance using phone-based global positioning systems (GPS), closed-circuit television (CCTV) surveillance, AI-supported technologies and data mining tools to locate the whereabouts of confirmed COVID-19 patients and to ensure compliance (Calvo, Deterding and Ryan 2020; Huang, Sun and Sui 2020; Wang, Ding and Xiong 2020). In the U.S., the Center for Disease Control has scaled up its COVID-19 surveillance systems (CDC 2020b) while numerous private companies collaborate with national and local governments or with other institutions to develop effective apps. Apple and Google, e.g., are building a (voluntary) COVID-19 tracking system into iOS and Android (Brandom and Robertson 2020) and other companies (e.g., Facebook) consider using data mining or facial recognition to trace patients and to enforce quarantine (Calvo, Deterding and Ryan 2020).

Surveillance through digital devices and data mining tools during the pandemic raises several issues, including privacy protections, the balancing between individual freedoms and collective good, and governmental powers in times of emergency. Some of these concerns are not new: existing digital technologies such as smartphones and related apps (e.g., Alexa) have been criticized for privacy infringement and surveillance that is often unbeknown to device-owners

(Kuruvilla 2019; Lutz 2019). But the use of existing and newly designed surveillance tools is only likely to increase in the COVID-19 era; the challenge is what forms it will take and what the limits of such uses will be (Alwashmi 2020; Calvo, Deterding and Ryan, 2020). What level of privacy infringement is acceptable for securing efficient contact tracing and compliance with public health measures? Concerns about over-intrusive methods emerged, e.g., with the possibility that New York City will adopt SafeTrace, an app that was developed by a private, for-profit company called Citizen that uses a combination of GPS location data, Bluetooth low energy, WiFi fingerprinting, and Cell Tower triangulation (Powers 2020). Should the downloading of surveillance apps onto personal devices be voluntary or mandatory? And how can such surveillance tools be enforced, by whom, and what would be the punishment for those who defy the order? In the U.S., all app-developers to date have focused on voluntary buy-in, though as we move forward, decentralized mandatory approaches are plausible. For instance, employers may decide to install contact tracing apps on the companies' devices (as has occurred, e.g., in Italy's UBI Banca) and colleges may require incoming students to do so as part of their plan for safe reopening (Farronato et al. 2020). Nationally, these questions and challenges are further fraught. Although high voluntary compliance was reported in countries with high trust in the government (e.g., South Korea, Germany (Korea Centers for Disease Control and Prevention 2020b; Miller 2020)), and mandatory surveillance is possible in countries with authoritarian regimes (e.g., China), the U.S. is fundamentally different. Stringent privacy laws make mandatory tracing systems a challenge, while public distrust in the government is currently at historic highs (Pew Research Center 2020).

Based on research in the psychology of surveillance in the context of cancer treatment (Carter et al. 2015), it has been suggested that patients may endorse a strict health surveillance regime once they understand its value (Calvo, Deterding and Ryan 2020). Yet, it is unclear if communities at large (rather than individual patients) will be similarly adaptable to endorse such a regime. Although it can help curb the pandemic, downloading surveillance apps into private devices may permit large-scale policing of racial and ethnic communities that are already disproportionately, and to their detriment, being surveilled. As scholars have observed, aggregated use of digital data may further result in group-level harms, including increased profiling of certain groups, stigma and discrimination (Yu

and Juengst 2020). And while the high morbidity rates among especially Blacks/AAs, Latinxs and AI/ANs may mark them as inherently “at risk” and in need for surveillance, the documented racial and ethnic bias in the use of genetic surveillance systems in the criminal justice context (Grimm 2007; Kreag 2015) raises a concern that similar biases will be replicated in the COVID-19 pandemic. Beyond a concern, emerging incidents of mask-wearing profiling (Cineas 2020), social distance policing (Southall 2020), and aerial surveillance of Black Lives Matter protesters under the pretext of COVID-19 contact tracing (Schwartz 2020), highlight how quickly racially biased COVID-19 surveillance may be a reality.

The digital divide in the U.S. further challenges the practical success of a strict health surveillance regime. Although mobile phone ownership has grown significantly in the past decade, the prevalence of cellphone owners and Internet access for whom downloading apps would be impossible is higher in populations that are particularly vulnerable in the COVID-19 pandemic. These include older people (>65 years), individuals with lower income and educational attainment, and those who reside in rural communities (Perrin 2019; Pew Research Center 2019), including AI/ANs living on tribal land (Consumer and Governmental Affairs Bureau Report 2019). While there is hope that appropriate messaging of the values and collective health benefits from such a surveillance system will yield a larger number of buy-ins (Calvo, Deterding and Ryan 2020), a concerted effort to bridge the digital gap through provision of smartphones to those who cannot afford them, along with revisiting of Federal laws that preclude the provision of such devices to Medicare or Medicaid beneficiaries (Schwartz 2020), will be key for promoting equitable surveillance measures.

Implementing such a system must also be geared toward trust-building. This may include instituting measures to ensure that data from digital surveillance is not sold or used beyond the immediate needs of COVID-19, privacy protections to limit the amount of personal data shared with the public and keeping it separately from patients’ other medical information, and guarantee that the collected data will be deleted once no longer relevant. It must also be based on the highest ethical and legal standards of equality, nondiscriminatory application and transparency in developing unbiased algorithms to assure that the collected data will not be used to further disenfranchise historically marginalized communities. These issues can be rectified by including diverse populations in the testing of new

technologies, diversifying the workforce of algorithm designers and training developers and users of such technologies about the sociocultural and historical context of their work (e.g., through direct engagement with marginalized communities) (Benjamin 2019).

LINGERING HEALTH NEEDS AND LONG-TERM DISABILITY AMONG COVID-19 PATIENTS AND BEYOND

In all likelihood, the healthcare needs and prevalence of disabilities will increase in the post-pandemic period. Yet, without appropriate address, the individual-, familial- and community-level costs will be insurmountable for those who entered the pandemic in a vulnerable position.

Although information about the lingering effects of COVID-19 are still emerging, existing data and knowledge from other respiratory diseases indicate that COVID-19 patients may experience short- and long-term disabilities. These include cardiac diseases (Kochi et al. 2020), impairment of pulmonary function (Mo et al. 2020), delirium and renal disorders requiring dialysis (Adapa et al. 2020; Goldberg et al. 2020). A significant number of ICU patients (estimated at 25–62%) may experience post-intensive care syndrome, encompassing cognitive impairments (e.g., memory loss, poor concentration), physical impairments (e.g., poor mobility, recurrent falls), and psychiatric conditions, especially depression, anxiety and post-traumatic stress disorder (PTSD) (Heneka et al. 2020; Rawal et al. 2017).

The health costs associated with the pandemic are further likely to expand beyond individual COVID-19 patients. Delays in routine and urgent medical care (e.g., cardiac conditions) may have long-term health impacts for non-COVID-19 patients (Vieta, Perez, and Arango 2020; Rosenbaum 2020). Although telemedicine has been useful in mitigating some of the challenges, this option may have been costly and difficult to others. Some of the challenges are systemic, e.g., payment systems and regulations that permit only in-person rather than remote care, some of which have been transformed and are now reconsidered for post-pandemic, including for Medicare recipients (Bosworth et al. 2020; Butler 2020). Other issues are likely to have a negative impact on already marginalized populations. Telemedicine may be unworkable for those who do not own a digital device, are technologically illiterate or distrustful of technology, and those who live in crowded living arrangements where privacy is practically non-existent (George, Hamilton and Baker 2009; Hong et al. 2020; Vieta, Perez, and Arango 2020).

The incidence of mental health conditions is also likely to increase among family members and communities (Vieta, Perez, and Arango 2020). Family members caring for COVID-19 patients at home may have faced the impossible dilemmas of when to seek professional care for which they may not be able to pay, how to balance between caring for sick family members and protecting their own (and other family members') health, and how to deal with deaths, not only of COVID-19 family members who died in hospitals, but also of numerous "probable" COVID-19 victims who died at home (in NYC, e.g., such latter deaths are particularly high among Black/AAs and Latinx (NYC Health Department 2020)). With reports on mass burials of unclaimed COVID-19 patients (Sisak and Minchillo 2020), the mental health toll may be further compounded for family members who were disconnected from and are trying to learn what transpired to their loved ones.

Finally, a spike of disabilities is likely to occur among COVID-19 first responders, including health-care providers, nurses, paramedics and other "essential workers" (e.g., grocery store employees). Beyond COVID-19 illness itself, they are at risk for developing anxiety, depression and PTSD due to their increased risk of contracting COVID-19 and exposure to outcomes of the pandemic (Lai et al. 2020; Muirhead 2020; Vieta, Perez, and Arango 2020). In the U.S., these risks are likely to disproportionately affect racial and ethnic minorities: most of the "essential workers" workforce, including some areas of healthcare such as nurses and medical assistants are nonwhite (U.S. Department of Health and Human Services 2017). Black/AA, Latinx and AI/AN healthcare providers may experience an additional trauma, observing firsthand the unconscionable impact of health disparities and disproportionately high mortality rate among members from their racial and ethnic communities.

Moving forward will require instituting immediate and long-term measures that consider historical and contemporary wrongs. Ensuring access of COVID-19 patients to high quality and affordable follow-up treatments and multidisciplinary rehabilitation and mental health services will be critical to allow recovery and to reduce the overall burden of disease. Some strategies to this effect do not require a significant reform in the current system. They can include, e.g., the use of federal waivers that allow states increased flexibility in the management of the healthcare system, expansion of urgent care centers and walk-in clinics to allow better locations for care, expansion of health insurance coverage to include telehealth for a range of routine

health-related services, and improvement of mechanisms allowing for budget flexibility in healthcare delivery by removing bureaucratic barriers and increasing multi-agencies collaborations (Butler 2020).

A process for post-burial forensic DNA identification of unclaimed COVID-19 victims and repatriation of the remains from mass burials may similarly be needed. In addition to its healing component (Johnston et al. 2019; Nelson 2016), mistakes in identification of COVID-19 deceased have already been reported (Otterman and Watkins 2020). However, such a process raises unique practical, legal and ethical dilemmas. It is unclear, e.g., if tissues from the unclaimed deceased have been consistently collected, and if not, what alternatives for post-burial identification might be. Although seeking bodily tissues that were collected from the deceased in other contexts (e.g., research participation, direct-to-consumer genetic testing) may aid repatriation, existing databases may be fraught with challenges.

Some research projects, and all NIH-funded studies since January 2019 (including enrollees in the All of Us Research Program), have obtained a Certificate of Confidentiality. Without the deceased's prior consent, the use of biospecimens collected as part of research studies for post-burial identification may be prohibited or require a judicial order that may not be affordable to all. Other existing datasets may have more permissible use policies, but they may be unhelpful or objectionable. Ancestry testing companies, e.g., may hold large datasets of biospecimens but they comprise mostly Whites (Holger 2018; Popejoy and Fullerton 2016), and they may not match the demographic characteristics of unclaimed deceased (racial and ethnic data are not available). Conversely, datasets held by law enforcement agencies, such as CODIS, are charged due to their racial profiling and disproportionately high surveillance of racial and ethnic minorities (Kim et al. 2011; Wagner 2017). Developing a process that balances values, interests, and legal regimes will be essential to facilitate the recovery of family members.

However, access to care and post-burial forensic DNA identification should only be first steps for recovery, and beyond the focus on individuals, there is a need for community-level healing.

NEXT STEPS: COMMUNITY ENGAGEMENT AND TRUTH AND RECONCILIATION COMMISSION

The pandemic's disproportionate impact on historically marginalized communities is a snapshot of a

moment in history that requires ethical, legal and political reckoning. We draw on two intersecting areas of research—i.e., community engagement in precision medicine research and truth and reconciliation commission for human rights abuses—to inform the next steps.

Community Engagement in Precision Medicine Research

Culturally competent community engagement will be instrumental for addressing COVID-19 related issues: it demonstrates respect and it is vital for promoting health equity (National Academies of Sciences Engineering and Medicine 2017). It is also a first step for building trust (NIH 2017), a key issue in preparing for future pandemics. As studies in precision medicine research have shown, distrust is a major barrier for research participation and healthcare provision among racial and ethnic communities and other marginalized groups (e.g., people with disabilities) (Bentley, Callier, Rotimi 2017; Erves et al. 2017; Passmore et al. 2019; Yeh et al. 2020). Moreover, the knowledge of incidents of mistreatment of one racial group (e.g., Tuskegee Syphilis Study, Henrietta Lacks) contribute to mistrust among *both* Blacks/AAs and across racial and ethnic minorities (Kraft et al. 2018).

The forms of community engagement can vary. In precision medicine research, community engagement projects are aimed at building on local knowledge to identify needs and interests of relevant communities, increase the involvement of historically marginalized populations that have been underrepresented in research, and ensure that research design and outcomes are culturally sensitive (Erves et al. 2017; Sabatello 2019). Beyond research design and participation, community engagement can inform key decisions and policies in particular arenas. For instance, a deliberative democracy approach has been used in the past decade in various genomic contexts, including surrogate consent for dementia research (De Vries et al., 2010), biobanking governance and informed consent practices (O'Doherty, Hawkins, and Burgess 2012; Garrett et al. 2015; De Vries et al. 2019), RDX pollution and microbial genomics (O'Doherty et al. 2013) and health systems and science implementation more generally (Burgess 2014). Although a deliberative democracy approach has challenges (De Vries et al. 2011; Kim 2016; Safaei 2015), its strength lies in the prospects of soliciting public perspectives on controversial issues and obtaining real commitment of the authorities to public input (Safaei 2015).

Community engagement can—and should—facilitate decisions in a range of issues related to the COVID-19 pandemic. In the immediate period, creating local community-based committees can help determine policies relating to data collection and the acceptable scope of research conducted with biosamples from COVID-19 patients, including procedures to inform families about the use and storage of autopsy specimens, which are often culturally-laden (Lee et al. 2019). These community-based committees should also establish guidelines to determine what is “fair and equitable benefit-sharing” and to develop actionable procedures to ensure that marginalized communities can reap the benefit from research. Early address of this issue is critical, and it should be led by racially-, ethnically-, and (dis)ability-diverse committee members who are numerically sufficiently powerful to impact the decisions.

In the long run, community engagement will be vital for identifying measures to reduce the possible harms associated with COVID-19 research and its aftermath. These should address the issues discussed earlier, i.e., lineage testing, digital contract tracing, surveillance methods, and individual- and community-level health needs, as well as informing procedures for post-burial genetic identification and access to healthcare more generally. However, the list of issues should be flexible to allow for community input on other issues that emerge (e.g., vaccination). As we describe below, such efforts require local, state, and federal level coordination and future-looking processes of reconciliation of historical wrongs.

Truth and Reconciliation Commission

Truth and reconciliation commissions (TRCs) have a long history in transitional justice. Initially, TRCs were developed by newly emerging and fragile democracies to present formal account of significant human rights violations such as torture, enforced disappearance and extrajudicial killings (usually by military or other governmental forces) (Avruch, 2010). However, they have evolved over time in scope and sources of establishment. In 2008, e.g., Canada—a long time democracy—established a TRC to guide the country through the process of coming-to-grips with its historical abuse of indigenous peoples and to lay down the foundation for reconciliation (Government of Canada 2019). Notwithstanding some criticism about such Commissions (e.g., whether restorative rather than retributive (punitive) justice is sufficient, as Black Africans voiced in South Africa (Allais 2011;

Tepperman 2002)), they are invaluable in their goal of assuring that acts of oppression and abuse as experienced by individuals and communities are inscribed onto a public record and into a social memory (Avruch 2010) as well as their future-looking nature (Minow 1998) that require a commitment—demonstrated by immediate, actionable steps—to transform the relationship between the parties and rectify formal and informal structures of power imbalance.

Although the U.S. is neither a fragile democracy nor in the process of moving from a totalitarian to a democratic regime in its state and Federal governance structures, its healthcare system displays characteristics of an authoritarian regime. As scholars have observed, it was established by the powerful few—i.e., White, male physicians and administrators; it is controlled by private, corporatized bureaucrats who are segregated by class, gender and race from the general public and from workers from lower socioeconomic strata; and it has largely been a closed system, resistant to change and to the democratization of healthcare management (Ballou and Landreneau 2010). Although the Patient Protection and Affordable Care Act expanded access to health insurance to some underserved populations, it maintained the privatized healthcare system and considerable racial and ethnic gaps in insurability (Buchmueller and Levy 2020). Concurrently, challenges to the Act have been sprung by elected representatives who often have a secured, lifetime access to healthcare benefits for them and their families. These efforts are ongoing, even as the negative effects of health disparities on COVID-19 morbidity and mortality are glaring, and millions of newly laid-off individuals have lost their health insurance during the pandemic (Dorn 2020). The democratic nature of our healthcare system thus also needs to be questioned on the grounds of its double standard for the haves and have-nots.

The pandemic's outcomes for marginalized racial and ethnic minorities highlight that this public health tragedy does not stand on its own. Rather, it is the apex of historical social, economic and political forces that have perpetuated and continue to impact the present deprivation among especially Black/AA, Latinx, and AI/AN communities in the U.S. The pandemic adds a "spectacle" to the silenced but well-documented intergenerational trauma among these communities. It adds a visual display of the historical experiences of trauma from slavery, displacement, colonization and genocide that are "passed on" from one generation to the next through a combination of biological, behavioral and psychological processes

(Chavez-Dueñas et al. 2019; Estrada 2009; Garcia 2020; Landor and McNeil Smith 2019; O'Neill et al. 2018; Yehuda and Lehrner 2018). Significantly, research highlights the role of structural factors that play into the cycle of continued trauma, including lack of access to adequate and preventative healthcare and the chronic stress associated with social disadvantage and racism (AAFP 2019; Scorza et al. 2019; Trent, Dooley, and Douge 2019). The COVID-19 pandemic offers a historical opportunity to intervene in this cycle and to make a change.

A detailed proposal for a TRC in the U.S. is beyond the scope of this article, but existing scholarship can inform the process. For instance, the TRC should clearly specify the scope of discussion, conducted within a relatively short time period (6 months – 2 years), instruct about the processes for public recognition and apology, and be authorized to issue actionable and binding measures for reconstruction efforts that encompass local, state and federal level of governance (Avruch 2010; Minow 1998). In particular, the TRC's work could be framed around healthcare systems and health outcomes. Such a focus is sufficiently narrow to allow for specific measures of accountability to emerge while being broad enough to include a holistic discussion on the factors that affect health outcomes. This discussion must address the underlying causes of systemic inequalities. It should include, e.g., assurance of universal access to healthcare (which can be done on the state-level, as in Massachusetts), local investment in creating and delivering healthy food options in poor neighborhoods (Brooks 2014), and socioeconomic policies to address overcrowded housing arrangements and low homeownership by people of color (Essien and Venkataramani 2020).

To fulfill its mandate, the TRC should hold public hearings to collect testimonies from all stakeholders and identify acceptable processes for reparation and reconciliation. Although public hearing proceedings are time consuming, they are important for the public recording of painful historical truths and for the healing process (Avruch 2010; McGibbon 2019). The TRC should comprise of diverse members, led by leaders from underserved and well-served populations, and provide historical information and cultural competency training before the beginning of sessions to address misperceptions that all members of the committee may have.

Healthcare management and service providers also must be included in these efforts (McGibbon 2019). Although the need for cultural competency in research

and healthcare has been increasingly recognized (Abrishami 2018; Sabatello 2019; Truong, Paradies, and Priest 2014), there are numerous studies demonstrating racial bias in the access to and provision of healthcare (Hall et al. 2015; IOM 2003; Maina et al. 2018). While workforce diversity is considered an effective way to reduce biases and health disparities (AAMC 2017), Black/AAs, Latinxs and AI/ANs account for only, respectively, 5%, 5.8%, and 0.3% of active physicians (AAMC 2019), far below their relative proportion in the adult population (respectively, 13.4%, 18.5% and 1.3% (US Census Bureau)). And, both the design of our healthcare system and the nature of medicine may entangle clinicians wittingly or not with structural racism. In South African's Apartheid, e.g., clinicians often cooperated, or were complicit with, a segregated healthcare system, public health policies that ignored diseases affecting primarily Black people, and a political system that systematically denied social determinants of health (e.g., clean water supply) to the Black population (Chapman and Rubenstein 1998). Diversifying the clinicians' workforce, ensuring cultural competency (Jooma et al. 2019), and providing incentives for clinicians who speak up against social injustices are some actionable measures that hospitals and healthcare systems can adopt to support the transition into a more equitable healthcare system.

These challenges are widespread in all sectors of society and highlighting them here does not intend to single out clinicians. In all likelihood, many clinicians agonize over these issues, an emotional burden that may contribute to the well-documented crisis of clinicians' burnout (Hartzband and Groopman 2020). However, this discussion aims to underscore why clinicians are key stakeholders in efforts to address racial and social injustice—and the need for them and medical institutions to be allies in the fight against structural racism (Issaka 2020). The experiential translation of deep health disparities in the U.S. into high rate of morbidity and mortality among especially Blacks/AAs, Latinxs and AI/ANs, alongside the dedication of healthcare providers to the treatment and recovery of COVID-19 patients should serve as a springboard for change.

Moving forward to establish a TRC may face challenges. Such Committees are usually created through a process of political transition to democracy and a decree of the new government. In the U.S., the lack of a transitional context may raise questions about legitimacy (Androff 2012a), while obtaining a national

governmental decision may be difficult in the current atmosphere of political polarization.

Nonetheless, there is room for hope. There are precedents in the U.S. for creating national commissions to respond to racial-based abuses, such as the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Although challenges to the implementation of the Commission's policies exist (Fisher 2020), the Commission's power could be improved through Congressional action (Capron 2017). There are also successful examples of local- and state-level TRCs to rectify issues of institutional discrimination (e.g., Maine-Wabanaki State Child Welfare TRC). The underlying reasons for and experiences of TRCs in the U.S. and Canada further make them particularly promising to effectively address structural racism. Such TRCs have been characterized by grassroots and community-based mobilization rather than the traditional top-down approach and their focus has shifted from processes to create democratic institutions to investment in human security more generally (Androff 2012a; Centala 2016). They have also shown to have a positive healing power (Androff 2012b). Local and international organizations, including the Black Lives Matter movement, and a growing public awareness of and commitment by large corporations (including some pharmaceutical companies) to address structural racism may thus result in sufficient political pressure to take an action (McGirt 2016; Sagaonowsky, Blankenship, Bulik 2020). Similarly, municipal governments are beginning to respond: City Council of Asheville in North Carolina, e.g., has recently approved reparations for Black residents (Vigdor 2020). As major national health associations have now recognized the presence of "racism in its systemic, structural, institutional, and interpersonal forms" as an urgent threat to public health and health equity, and pledged to confront systemic racism and police brutality (e.g., AAP 2020; AMA 2020; APHA 2020; ASHG 2020; Blue Cross Blue Shield Association 2020), we have an opportunity to redesign the status quo.

CONCLUSIONS

The COVID-19 pandemic gives a face to decades of segregation, racism and structural discrimination. It forces us to look to the generations of especially Blacks/AAs, Latinxs and AI/ANs that have often endured mistreatment in all aspects of life—from limited educational and employment opportunities to

high levels of poverty and environmental neglect, insufficient, often absent, access to basic healthcare services, police brutality, and overrepresentation in the criminal justice system.

The opportunities for moving forward are plenty. Although the COVID-19 pandemic raises numerous questions, it intersects with other areas in which there is an abundance of knowledge that can inform the discussion. In this article, we drew on scholarship in genomics to highlight challenges that are likely to arise. These include collection, use and storage of data for research, fair and equitable access to the benefits of research, testing and surveillance concerns, and lingering healthcare needs and long-term disability among individuals, families, and communities at large. Community engagement and multi-leveled commitment will be vital for ensuring tailored and culturally sensitive approaches to assure that historical wrongs are addressed and remedied. The COVID-19 pandemic calls for self-reflection, broad public engagement and cultural humility to transform our troubled health, socioeconomic and political infrastructures into a sustainable, equitable and prosperous society for all.

DECLARATION OF INTEREST STATEMENT

Maya Sabatello is a member of the All of Us Research Program's Institutional Review Board. The authors declare no other conflict of interest.

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