**A Proposed Framework for Addressing Social Justice Concerns in Future Digital Biomarker Research**

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Short Title: Social Justice in Digital Biomarker Research

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**1.** **Abstract:**

Digital biomarker researchers have a crucial role to play in ensuring that digital biomarker studies do not perpetuate health inequities across race and socioeconomic status in the United States. This role can be conceptualized as adhering to appropriate standards of social justice. We explore what social justice constitutes in the digital biomarker context and how these standards can be achieved with minimal changes to how digital biomarker research is conducted. These changes can be grouped into three main types corresponding to the types of actions that should be undertaken by digital biomarker researchers during the research process. First, we argue that concrete goals should be set for participant diversity within digital biomarker research. Second, we recommend increased diversity among digital biomarker researchers and/or research advisors. Lastly, the importance of inclusive research locations is considered. We also examine potential inequities related to the distribution of digital biomarker technologies.

**2. Keywords:**

Digital biomarkers; diagnostic methods; social justice; research ethics; medical ethics

**3. Background:**

Substantial inequities based on race and socioeconomics exist in healthcare, both nationally and worldwide (Marmot 2017; Chokshi 2018; Mays, Cochran, and Barnes 2007; Ruger 2004). We consider inequities based on race and socioeconomics because a wealth of data is available on these types of inequities and because they are deeply interrelated problems (Marmot 2017; Mays, Cochran, and Barnes 2007). Our subsequent analysis will be most applicable to digital biomarker research in the United States because that is the source of most of our experiences and of most of the references we draw upon, yet our suggestions are broad enough that they might also be advisable elsewhere in places with similar healthcare inequities and similar possibilities for technological solutions.Digital biomarker technologies have a unique role to play in ensuring underserved communities (communities that bear the burdens of inequities) receive equitable medical treatment compared to medically advantaged communities (communities that receive benefits from inequities). In particular, digital biomarker research can be used to reduce health inequities in two key ways. First, digital biomarker researchers can address racial and socioeconomic diversity and inclusivity in their studies. Underserved community members face different medical problems, and to different extents, than their advantaged counterparts (Chokshi 2018).Second, it is important that digital biomarker technologies are equitably distributed to the public. Dorothy Roberts points out the pitfalls of pursuing more equitable medical care by targeting specific ethnic and racial groups during biomedical research (2010). Roberts believes this approach can result in more pronounced social inequity if benefits from research advances are only accessible to the privileged few. Other targeting efforts such as those employed by the *All of Us* research program likely fail because they only consider superficial differences between groups of people rather than more substantive ones. In fact, if one visits the community resources page under the joinallofus.org domain, what is noticeable, with minimal inspection, is the flyers targeting different racial groups are identical except for the pictures depicting people from those racial groups. This demonstrates a misunderstanding of culture and diversity at the highest levels of research governed in the US. This, coupled with the biases of modern technology, emphasizes the need for policies and procedures to address social justice in digital health technology research. These social justice issues have been overlooked in previous discussions of digital biomarker ethics. Given this, a new social justice framework is necessary to properly address these issues as they pertain to digital biomarker research.

Gostin and Powers believe social justice includes “fair disbursement of common advantages and the sharing of common burdens”(Gostin and Powers 2006, 1054). Considering the relationship between social justice and health, they assert social justice requires “health improvement for the population and fair treatment of the disadvantaged”(Gostin and Powers 2006, 1054). These definitions have the advantages of being both intuitive and nuanced. They capture the intuition that health should be accessible to all while also asserting that disadvantaged people and groups should sometimes be prioritized. As such, the phrase social justice will be used in this paper in accordance with these definitions.

A biomarker is defined as “a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacological responses to a therapeutic intervention”(Naylor 2003, 525). Digital biomarkers are biomarkers that have been recorded digitally (Wroge et al. 2018).

Human voice can act as a digital biomarker because links have been found between vocal patterns and numerous diseases including Parkinson’s, Alzheimer’s, and depression (Wroge et al. 2018; Gold et al. 2018; Nelson and Allen 2018). Our previous work in these areas (Wroge et al. 2018) has demonstrated existence of a relationship between automatically extracted voice features with objective and subjective measures of disease typically used in clinics (e.g. the Unified Parkinson’s Disease Rating Scale). In the case of Parkinson’s, we previously demonstrated the relationship between specific acoustic features and the motor symptom portion of the scale. These voice-based digital biomarkers can be used to create new, non-invasive screening and diagnostic methods for these and other diseases (Naylor 2003; Wroge et al. 2018; Gold et al. 2018). As such, they have the potential to prevent and cure disease for both those who are underserved and those who are not.The current proposal will focus on voice as the paradigm for digital biomarkers.

There are several different ways in which digital biomarker technology might function, including both consumer-facing and provider-facing systems. In a consumer-facing system, an app or a wearable device would be used to sample and analyze patients’ voices in their everyday lives (Gold et al. 2018; Nelson and Allen 2018; Pittman, Ghomi, and Si 2018). The technology would then alert medical professionals if signs of disease were detected and care could be provided. Alternatively, a provider-facing system might be employed where medical professionals would be the only ones with digital biomarker technology in their possession (Gold et al. 2018). If this was the case, patients told by medical professionals they might have certain diseases would be tested (in what might be a screening test) by the medical professionals, much like existing tests which require a physician order (e.g. blood tests).

Here we consider ethical ramifications related to digital biomarker technologies that must be considered. The ethical issues involved include privacy, confidentiality, and social justice (Lucero et al. 2015). Previous ethical frameworks have focused on the privacy and confidentiality aspects of digital biomarker ethics (“Digital Health Consumer Adoption: 2015” 2015; Coravos, Khozin, and Mandl 2019).The ethical framework in Martinez-Martin et al. examines the issues of accountability, privacy, transparency, and informed consent (2018). Although the study mentions the possibility of racial bias within digital biomarker research, it does not provide an account of how the potential for racial bias should be addressed other than by an increase in data transparency. We believe these frameworks are incomplete because they inadequately consider social justice concerns.

In particular, we have concerns regarding the diversity of voice datasets (Tatman and Kasten 2017). The lack of diversity in the datasets used to train voice recognition models results in those models being less useful for underrepresented communities (“The Accent Gap” 2018; “Alexa and Google Assistant Are 30% Less Likely to Understand Non-American Accents” 2018; Reynolds 2017; Paul 2017). For example, current commercial voice recognition products such as Apple’s Siri, Amazon’s Alexa, and Google Assistant perform worse if a non-white speaker uses them (“The Accent Gap” 2018; “Alexa and Google Assistant Are 30% Less Likely to Understand Non-American Accents” 2018; Reynolds 2017; Paul 2017). Similar critiques have been made across a number of technologies involving machine learning and artificial intelligence (Buolamwini and Gebru 2018). Current voice biomarker research in healthcare will suffer the same limitations if diversity within datasets is not addressed. Additionally, even where underrepresented community members could technically use digital biomarker products it is not clear that they would be as beneficial for these people as for others who are adequately represented. After all, voices might be compared to standardized baselines without accounting for cross-cultural variation. In other words, communities that lack representation are likely to become underserved – or more underserved – as well.

As discussed earlier, underserved communities often suffer much worse patient outcomes than advantaged communities (Marmot 2017; Chokshi 2018). Digital biomarker technologies will affect these inequities necessarily, which is a powerful motive in itself for making sure inequities get reduced rather than increased. Yet these technologies will result in the reduction of inequities only if such reduction is made an explicit goal. Otherwise, digital biomarker technologies will amplify existing inequities in healthcare. It is imperative, then, that researchers developing digital biomarker technologies include and work to improve diagnoses for underserved community members. In what follows, a social justice framework will be introduced with the goal of showing how digital biomarker technologies can benefit a more representative proportion of the population and promote the welfare of the disadvantaged.

**4. Discussion:**

Here we present two broad approaches to ensure the potential benefits of digital biomarker technologies are accessible to underserved community members. First, medical research into new technologies should include underserved community members during all stages of the development of those technologies. Second, digital biomarker technologies should be equitably distributed to both underserved and advantaged communities. Our focus will be mainly on the first approach, although the second will be examined briefly. The first table below is a summary of our proposed social justice framework. Each aspect of this framework will be explained and analyzed in turn.

**Table 1 near here**

It is crucial that specific, attainable goals are set for participant diversity. Vague goals for increasing participant diversity are unlikely to effect change. Critics may argue that setting goals for participant diversity is a form of tokenism (Ocloo and Matthews 2016). While this is certainly a potential danger of this approach, setting goals for participant diversity may be less likely to be tokenizing if those goals are set in large part by researchers from underrepresented communities. It is exactly this concern that leads us to conclude that participation goals should be set with substantial input from underrepresented scientists and community members. These guidelines should then be published so that digital biomarker labs around the world have access to realistic goals that allow them to improve their research and act in a socially just manner.

Regarding the second section of the framework, more racial and socioeconomic inclusivity among digital biomarker researchers may lead to more racial and socioeconomic inclusivity among those participating in digital biomarker studies. One reason this might be the case is that research participants are more likely to identify with researchers with similar backgrounds and life experiences as their own (Sierra-Mercado and Lázaro-Muñoz 2018).Additionally, researchers from underrepresented backgrounds may be more likely to understand the concerns of underrepresented research participants (Sierra-Mercado and Lázaro-Muñoz 2018).For these reasons, it seems probable that underserved community members would feel more comfortable with and therefore more likely to volunteer their data to researchers from underrepresented backgrounds. The Lucero study – which investigated the views of urban-dwelling community members on clinical data use – supports the claim that research participants who are comfortable with researchers are more likely to volunteer their clinical data (Lucero et al. 2015).The concept of researcher inclusivity has also received considerable interest from the NIH (“NOT-RM-19-001: Request for Information (RFI): Institutional Accountability to Promote Inclusive Excellence” 2019).To be clear, we are advocating for enough researchers from underserved communities to meet the guidelines from the first section of the framework and not a specific number of researchers from these communities. This is because we wish to defer to the judgments of a diverse segment of the research community rather than unilaterally prescribe guidelines for representation and because digital biomarker labs will differ widely in how feasible it is for them to hire researchers from different backgrounds.

The last section of our framework addresses the differences in access to medical research locations between communities. Lack of adequate transportation frequently prevents underserved community members from fully participating in medical research (Syed, Gerber, and Sharp 2013). In our group’s work we have noted significant differences in demographics of participants based on location of recruitment. Our previous studies have recruited from numerous locations in the greater Seattle area and depending on proximity of public transportation and to specific neighborhoods the composite of the subject pool varies greatly (University of Washington et al. 2019). In our case we had success with sending team members with diverse backgrounds into neighborhoods and facilities where higher proportions of underrepresented people were present.

Prior to this we noticed the research subjects we recruited were much less diverse and even those from diverse racial and socioeconomic backgrounds may not have felt included. Another reason to believe this type of community-based approach can be effective is that it has been effective in recruitment for cancer prevention studies (Greiner et al. 2014).

As these examples demonstrate, there are good reasons to put less emphasis on trying to bring underserved community members to high-income areas where academic hospitals tend to be located (and therefore where medical research tends to be conducted). Researchers should gather more data in predominantly low-income and/or racially diverse neighborhoods. This approach is likely to lead to a more inclusive set of participants in medical research, resulting in a more diverse digital biomarker database.

The second table below summarizes how our social justice framework would help researchers ensure that underserved communities receive a more equitable proportion of benefits from digital biomarker technologies.

**Table 2 near here**

Turning to the second broad approach we propose, social justice also requires that underserved communities actually have access to digital biomarker technologies once these technologies are ready for commercial distribution. We argue that this is no less important than egalitarian research participation. If studies are diverse but distribution is not, then underserved communities will not have access to technologies that might be beneficial to them. On the other hand, if distribution is diverse but studies are not, then underserved communities might have access to technologies that are not beneficial to them. Clearly both sides of this equation are necessary to ensure that digital biomarker technologies are used to promote social justice. As such, it will be necessary to address issues related to the digital divide (Piatak, Dietz, and McKeever 2019).

As it pertains to digital biomarker development, equal distribution is doubly important because the accuracy of these biomarkers is iteratively improved through subsequent data collection from the users. If the ultimate user base is not diverse, inequity of accuracy for the biomarkers between racial groups is inevitable. As more advantaged people submit their data their biomarker accuracies will improve while those for underrepresented people will lag behind.

Furthermore, it is important that underrepresented and underserved voices are involved in ethical discussions regarding the development and use of these new technologies. If these voices are not involved in such discussions, the ethics community may only serve to reinforce inequitable medical outcomes. This reinforces the point that equitable research participation and access to technologies are necessary, but demonstrates that they alone are insufficient.

**5. Conclusion:**

We have discussed several ways in which social justice concerns related to digital biomarker research can be addressed. Our hope is that researchers will engage with this framework and adapt it to their individual needs while carefully considering the needs of others. If a social justice framework is properly employed, it becomes more likely that the benefits of digital biomarker technology will be available to a more significant fraction of the population and that the disadvantaged will be treated justly. Beyond the issues addressed above, special care must be taken toward the outcomes of any targeted research as to not create further inequity by improving technology for specific groups while the privileged few reap the financial rewards. There are organizations aiming to address this pitfall by creating individually owned human data infrastructures such that each person keeps their healthcare data and can share as they see fit (Tzovaras et al. 2019). This will lead the way to socially equitable advances without excessive privatization.

**6. Statements**

**6.1. Disclosure of Interest**

Dr. Hosseini Ghomi is a stockholder of NeuroLex Laboratories.

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**8. Tables**

**Table 1: How does the proposed framework address research participation?**

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| --- | --- | --- |
| Setting Attainable Goals | Including Underrepresented Researchers/Advisors | Choosing Accessible Research Locations |
| Specific, attainable goals for participant diversity should be made early in project development with substantial input from underrepresented researchers, advisors, and/or community members. | Labs conducting digital biomarker research should make efforts to include researchers from underserved backgrounds and/or recruit underrepresented research advisors. | Researchers should choose research locations that are accessible to underserved community members.  |

**Table 2: How does the proposed framework help researchers act equitably?**

|  |  |  |
| --- | --- | --- |
| Setting Attainable Goals | Including Underrepresented Researchers/Advisors | Choosing Accessible Research Locations  |
| Participation goals created in large part by people from groups traditionally left out of the research process would make it more likely that studies would accurately represent potential beneficiaries. This can only work, however, if researchers make every effort to reach these goals. | Better representation among researchers and research advisors is likely to lead to increased comfort among underrepresented research participants and subsequently higher participation rates among underrepresented groups. | More accessible research locations would increase the likelihood that underrepresented community members would physically be able to participate, which would lead to higher participation rates among underrepresented groups. |