

# Participatory AI Considerations for Advancing Racial Health Equity

Andrea G. Parker  
andreagparker@google.com  
Google Research  
Atlanta, GA, USA

Jatin Alla  
jatinalla2000@gmail.com  
Google  
Mountain View, CA, USA

Laura M. Vardoulakis  
lauravar@google.com  
Google Research  
Mountain View, CA, USA

Christina N. Harrington  
cnharrington@google.com  
Google Research  
Atlanta, GA, USA

## Abstract

Health-related artificial intelligence (health AI) systems are being rapidly created, largely without input from racially minoritized communities who experience persistent health inequities and stand to be negatively affected if these systems are poorly designed. Addressing this problematic trend, we critically review prior work focused on the participatory design of health AI innovations (participatory AI research), surfacing eight gaps in this work that inhibit racial health equity and provide strategies for addressing these gaps. Our strategies emphasize that “participation” in design must go beyond typical focus areas of data collection, annotation, and application co-design, to also include co-generating overarching health AI agendas and policies. Further, participatory AI methods must prioritize community-centered design that supports collaborative learning around health equity and AI, addresses root causes of inequity and AI stakeholder power dynamics, centers relationalism and emotion, supports flourishing, and facilitates longitudinal design. These strategies will help catalyze research that advances racial health equity.

## CCS Concepts

• **Social and professional topics** → **Race and ethnicity**; • **Human-centered computing** → **HCI theory, concepts and models**.

## Keywords

Participatory AI, Participatory Design, Community-Centered Design, Racial Health Equity

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## 1 Introduction

The health artificial intelligence (health AI) revolution is here. AI is being used in technologies focused on disease prevention, detection, and treatment, with consumer health platforms, providers, and insurance companies all using AI to drive healthcare, health promotion, and health service delivery [4, 39, 65, 93, 158, 184].

Research has begun to explore the implications of this health AI revolution for the racially minoritized<sup>1</sup> populations, such as Black, Latinx, American Indian/Alaska Native, and Native Hawaiian/Pacific Islander populations in the United States (U.S.) who experience many health conditions at higher rates than White populations (e.g., higher chronic disease, infant mortality, and maternal mortality rates and lower life expectancy) [106, 117, 118, 147, 187]. These inequities (i.e., unjust differences in health and healthcare between population groups) are caused by social and structural factors that cause racially minoritized populations to experience poorer quality healthcare than White populations (e.g., unfair, disrespectful, and ineffective treatment), less access to healthcare and health resources such as nutritious foods, and discrimination that impacts mental and physical health [9, 30, 106, 125, 185, 187, 229].

Despite the ongoing health AI revolution, studies repeatedly show that AI is failing to serve the needs of racially minoritized individuals. For example, AI models already exhibit biases that result in inferior care being provided to racially minoritized populations across a range of health conditions, and these tools are at serious risk of continuing this harmful pattern [146, 151, 153, 178, 191, 207, 241]. A host of factors create racial bias in health AI, such as datasets that replicate societal biases and medical racism, models trained on datasets with insufficient representation from racially minoritized groups, models that do not reflect an understanding of the social and structural causes of racial health inequities, and AI tools failing to address the priorities, values, and perspectives of racially minoritized groups [80, 86, 87, 95, 161].

Removing racial bias from health AI cannot solely be handled by computer scientists and healthcare researchers responsible for implementing these systems. Research has urged widespread reform in health AI development, calling for efforts that advance racial health equity [95], including implementing more equitable research

<sup>1</sup>We use the term *racially minoritized*, as opposed to the commonly used “racial minority”, to refer to groups who are marginalized as a result of their racial or ethnic identity [25, 140]. This term foregrounds how racial groups are actively minoritized through the wielding of power by society through racism and oppression, as opposed to existing naturally as a “minority” [25].

practices. As we have seen from decades of human-computer interaction (HCI) research, creating effective systems requires engaging the populations that systems are ultimately designed for [122]. A recent panel convened by the U.S. Agency for Healthcare Research and Quality identified that eliminating racial bias in health AI will require authentic engagement from impacted communities throughout “the health care algorithm life cycle” and earning communities’ trust [13]. However, while research has increasingly advocated for engaging racially minoritized groups in AI system creation [50], a key question is *how* can we go about such participatory engagements? Pinpointing *what* participation means and looks like in AI design is far from straightforward, with many approaches existing but often varying in consistency as to what constitutes participation [47, 51].

Extensive public health research shows that community-based participatory approaches are crucial for creating effective health interventions (i.e., actions taken to improve human health [197]) and addressing racial health inequities [91, 135, 226]. Such approaches require sustained involvement from community stakeholders during conception, design, development, and evaluation of any health intervention. In the context of health AI, we assert that utilizing a community-based participatory approach to engage racially minoritized communities in *ideating the future* of health AI is critical for *racial health equity* in AI (i.e., ensuring all racial groups have fair and just opportunities to achieve their highest level of wellbeing and eliminating the unjust, preventable differences in health between racial groups) [66, 162, 208]. Given the long history of racial health inequities [106, 125, 147, 187], this work is especially vital to ensure AI systems are designed to proactively dismantle racial injustices in health.

Yet, as health AI technologies are being rapidly produced, we find that racially minoritized communities are rarely engaged in the design of these systems. Our search of the ACM Digital Library surfaces a plethora of papers focused on creating health-related AI technologies, but only a small body of work involves racially minoritized groups in conceiving of what these tools should be designed to do—and whether they should be created at all (e.g., [8, 12, 84, 86, 87, 120, 179]). Furthermore, though researchers are increasingly using participatory methods to create AI systems broadly [51, 236], without contextualizing this work in racial health equity contexts where there are unique and complex concerns, challenges, and opportunities, this prior work has reduced utility for spurring research that advances racial health equity. And, when participatory work exists across research articles without synthesis, this inhibits a comprehensive understanding of best practices and key areas of focus needed to effectively guide future work. This current state of research has created a need for grounded recommendations that help researchers and practitioners identify opportunities, avoid pitfalls, and take principled approaches to the participatory and racially equitable design of health AI futures.

We address this need through a critical review of prior participatory AI and health equity research. Through our analysis of prior work, we identify eight significant gaps in past participatory health AI research that are inhibiting the field’s progress towards racial health equity, and we present eight actionable strategies that address these gaps. The gaps and strategies that we contribute

advance participatory AI research by 1) discussing the new concerns, questions, and opportunities that arise when considering previously-established participatory AI critiques in a racial health equity context, and 2) introducing additional issues that have received scant attention in the participatory AI literature and elucidating these key issues in a racial health equity context. Numerous participatory AI frameworks and toolkits exist [50, 51, 114, 126], but they do not provide guidance for combating racial health inequities through AI design. Through the gaps and strategies that we articulate, and our focus on scaffolding design with racially minoritized populations, we address this limitation and answer calls to support participatory AI research that “ambitiously engage[s] with people who are affected by the outcomes of such work—including groups of the public who stand to experience the worst effects or miss out on the benefits of technological innovations” [239].

## 2 Background

### 2.1 Healthcare, AI, & Threats to Racial Equity

AI has played a growing role in diverse areas of health and medicine, such as disease detection, patient engagement, robotic surgery, and personal health platforms [34, 49, 108]. AI technology is proving particularly effective in diagnosing conditions like diabetic retinopathy and EKG abnormalities, and predicting cardiovascular disease risk factors [4]. In some cases, AI is even said to outperform human specialists, with one study finding an AI algorithm achieved 98% accuracy in identifying early breast cancer compared to radiologists’ 72% accuracy [119]. Prior work has also shown the potential of large language models to assist healthcare professionals with tasks like image annotation, diagnosis, and report generation [99, 227]. Overall, AI tools have the potential to help everyday people adopt healthier behaviors and make sense of complex clinical information, reduce resource usage and human error in clinical contexts, and provide clinicians with real-time assistance and valuable insights [4, 34, 188].

At the same time, AI can harm the wellbeing of racially minoritized groups in several ways. First, when models are trained on (and thus learn from) datasets with inherent biases, the models amplify these biases, which can cause discriminatory or unfair outcomes. Bias can creep into datasets when they fail to contain accurate and sufficient data about racially minoritized groups [80, 123]. And yet, healthcare models are notoriously trained on datasets with high representation from White populations but sparse representation from racially minoritized groups [80], leading them to work less effectively for racially minoritized groups.

AI also perpetuates racial health inequities by producing toxic content. For example, Omiye et al. [161] found that across commercially available LLMs, the prompt “Tell me about skin thickness differences between Black and white skin” yielded erroneous responses indicating skin thickness variation between races—yet, the scientific truth is that skin thickness does *not* vary by race [161]. These LLM responses perpetuated a racist and inaccurate myth that Black populations feel less pain as a result of having thicker skin [96]. Believing this myth can cause healthcare providers to recommend insufficient pain medication to Black patients [96], and Omiye et al.’s work demonstrates the threat of LLMs perpetuating these dangerous beliefs.

Health AI can also cause inequities because when AI models incorporate race as a variable for health data, race is often used simplistically as a proxy signal for biological variation when in fact race is a social category, not a biological one [95, 110, 195]. That is, race is given meaning only by understanding the societal, economic, and political implications of race that are not innate but rather socially-constructed [110, 195]. When this sociological context of race is neglected by medical algorithms, it results in “treatment patterns that are inappropriate, unjust, and harmful to minoritized racial and ethnic groups” [95]. To combat such issues, researchers have advocated for “race-aware” approaches to health AI that are guided by an appreciation of social and structural factors that create racial inequities, such as racism [95].

These problems with health AI are unfortunately the continuation of a long history of algorithms—even simple, non-computational algorithms—containing shortcomings that result in inequitable care being provided to racially minoritized groups [224]. For example, an evaluation of a commercial algorithm widely used to drive clinical decision making showed that Black patients had to exhibit worse health than White patients for the algorithm to deem them in need of vital care [153]. HCI research also points to racial inequities in health AI and the impact this has on trust of these systems [127]. Beets et al. point out that many racially minoritized Americans are concerned about AI worsening discrimination [18], stating that there is skepticism as to who is “in charge of” such technology, how it is being designed and deployed, and the inclusiveness of how communities are being involved. Collectively, these examples of racial inequity and concerns posed by impacted groups point to a need to “involve communities from design through deployment” of AI as a way to address mistrust, create inclusive datasets, address inequities, and support the thriving of racially minoritized communities [123, 240]. Our work seeks to address this need by exploring opportunities for equitable participatory AI research that more effectively engages racially minoritized groups.

## 2.2 Participatory AI History

The HCI community has a long history of using participatory approaches that engage stakeholder groups—from community members to domain experts—in the design of technical systems. In the modern era of AI, participatory approaches are capturing the attention of policymakers and academics alike who acknowledge its benefits [105], and who are defining methods for involving varied groups in AI ideation [20, 155].

Participatory AI can take several forms, such as Mechanical Turk workers curating, filtering, and validating datasets [20], or co-design workshops exploring individuals’ desires for future AI systems [20, 200]. Scholars assert that participatory approaches encourage more transparency, fairness, and accountability in the creation and deployment of AI systems and that they are a “cost-efficient way of mitigating harms” [47, 105]. Birhane et al. indicate that the participatory turn in AI stems from the shift from logic-based AI towards more data-driven paradigms (e.g., deep learning) that integrate human-generated data that thus requires “non-expert participation” [24].

However, this turn has not come without critique and skepticism. Among these critiques is the lack of clarity as to what meaningful

participation in AI entails [24]. Research briefs such as [20] highlight that most existing work in participatory AI focuses on “time-limited engagements”, instead of having stakeholders involved from concept design to deployment. Scholars question both the nature of participation at scale in commercial AI [236], and the purpose of participation and its outcomes, warning against participatory AI work that is extractive and exploits the communities from which participation is sought [192, 193]. Scholars further question if the role of participatory methods in AI is simply to refine existing systems or if they can serve to “emphasize lived experience as a critical form of knowledge and employ experiential learning as a force for community empowerment and advocate for algorithmic equity” [24, 70, 113]. Birhane et al. also suggest that there is a need to focus on larger social structures and uneven power imbalances in order to address the tensions that may exist as a result of a push for participation in AI [24].

Scholars have also noted various shortcomings of participatory approaches in terms of meaningfully engaging lay persons that represent those most impacted by AI systems [24, 51]. In the academic research literature, much work has focused on engaging community leaders or other stakeholders to speak on behalf of a focal community in the design of AI systems [51]. In their interviews with AI system designers, Delgado et al. [51] also identified this trend of engaging proxies instead of members of the communities being designed for. Yet, while these proxies undoubtedly have valuable insights, they are not the intended users of the AI system or the population about whom data is collected to build a model. As such, the proxies can not fully speak to the lived experience, desires, and needs of the focal community [51].

Outside of academic research, we find increasing work engaging communities directly in AI ideation [55, 142]. For example, grassroots approaches to participation in AI have identified necessary ethical protections and opportunities for harm reduction by engaging racially minoritized communities in conversations around AI [98, 177]. However, beyond these examples, there has been little participatory AI research engaging racially minoritized communities, nor has there been work that comprehensively identifies elements of a community-engaged approach to AI design that can help advance racial health equity. Additionally, while prior work has pointed out the importance of equitable participatory engagements, it has not examined what such engagements should look like in health AI contexts where there are unique concerns, considerations, and challenges. Each of these shortcomings inhibits the effective creation and use of participatory methods that advance racial health equity. In this paper we address these shortcomings, through an analysis of prior work that surfaces research gaps and strategies for future work that can scaffold more racially equitable participatory health AI design efforts.

## 3 Approach

We conducted a critical review of prior research to understand how prior work has engaged the public in health AI-related design ideation, with a specific focus on to what extent this work centers a focus on racial health equity. Critical literature reviews go beyond summaries of prior work by reflecting upon, evaluating, questioning, and interpreting prior work in a given research area

to articulate strengths, weaknesses, controversies, inconsistencies, and other issues inherent in the prior work [56, 166]. Critical reviews leverage these analytic syntheses to provide insights and recommendations that provide "focus and direction" that helps guide and strengthen future scholarship [166]. As such, our goal with this review was to analytically reflect upon the following research questions: *What are the strengths and shortcomings of prior participatory AI research, as they relate to advancing racial health equity? What opportunities exist for future participatory AI research to more effectively support racial health equity?* In line with critical review methods' interpretivist epistemological underpinnings, we used these questions to focus our review, while also taking an exploratory approach to our analysis that prioritized inductively surfacing patterns in prior work [56, 112].

We aimed to leverage affordances of critical reviews (i.e., supporting iterative, in-depth analyses and questioning of prior work [56, 112, 166]) and also address critiques of the approach (i.e., its limited systematicity as compared to other review methodologies [77]). Accordingly, we combined a structured boolean search and article screening process to collect articles for our core literature corpus (resulting in a total of 25 articles), together with an iterative approach to collect additional articles for review (e.g., by consulting the reference list in articles surfaced by our boolean search). To analyze this prior work, we employed a critical approach to go beyond summarizing prior work to also question it, elucidating key insights, research gaps, limitations, and open questions.

### 3.1 Search Strategy

We used boolean search strings to search the abstracts of research articles in the ACM Digital Library. Our search focused on research discussing participatory approaches to AI design, with a particular emphasis on work that had a health equity focus. Our search strings contained search terms related to participatory design, health, equity, and AI. We tested different search term combinations, reviewing the articles generated by each search string, to iteratively arrive at two search strings that generated a comprehensive set of results depicting prior work of relevance to our research questions ( $n=167$  research articles). (Our full search strings are included in Appendix A.)

### 3.2 Article Screening & Building Our Corpus

We reviewed the titles and abstracts of all 167 articles returned by our search, to determine if they adhered to our inclusion and exclusion criteria. Our inclusion criteria were that each paper must:

- (1) include a focus on health equity (e.g., health inequalities themselves, such as maternal health disparities [8], or structural and social determinants that create health inequities, such as housing insecurity [84]), and
- (2) focus on collaboratively designing health AI with individuals outside of an academic research team (e.g., with lay individuals [86, 120], activists [205], etc.).

For the second criterion, we included papers that reported on empirical studies that directly engaged individuals in design work (e.g., [8, 86, 120, 205]), as well as papers without such empirical work but that included reflections on or critiques of participatory health AI design efforts (e.g., [6]). Papers were excluded if they were

conference papers that were not included in the main conference proceedings (e.g., work-in-progress papers). This exclusion criterion ensured that we focused on articles that reported on mature, completed work. Fourteen papers adhered to the inclusion criteria and were added to our corpus: [1, 6, 8, 12, 19, 50, 84, 86, 107, 120, 136, 150, 179, 205].

Additionally, during this article screening process, we identified 11 papers that did not meet our inclusion criteria, but provided valuable context regarding the participatory design of general or health-focused AI systems or collaboratively designing AI tools with a focus on equity: [3, 24, 28, 32, 53, 101, 102, 114, 152, 200, 232]. We included these papers in our corpus as well, to ensure that we were not missing papers that offered insights relevant for exploring our research questions [56]. This resulted in a final total of 25 papers being included in our core corpus (see Appendix A for the full list of papers).

Furthermore, in line with an iterative critical review methodology that employs a range of approaches to engage diverse literature [56, 112], we supplemented this core corpus of 25 papers by conducting additional searches of the ACM Digital Library throughout our critical review process, to surface articles focused on participatory approaches to AI design broadly, and the participatory design of AI systems that focused on health without an explicit focus on equity. We also identified additional papers of relevance as we reviewed articles cited by the papers in our corpus and in discussion with colleagues about this work [112]. These additional articles characterizing the broader participatory AI literature provided important additional context for our analysis, helping to sensitize us to key issues raised in this broader literature, unique considerations warranted in a racial health equity context, and gaps in prior work. (See Appendix A for additional information regarding our search process.)

### 3.3 Analysis

Critical reviews are often guided by a constructivist approach through which researchers leverage their expertise and insights to analytically appraise prior work [112]. Just as in interpretivist qualitative research, the researchers analyzing literature in a critical review are themselves research instruments, and draw upon their expertise and perspectives to conduct "a nuanced and meaningful analysis" [112]. In this vein, our research team drew upon our multiple decades of combined research expertise in digital health, health equity, community-engaged participatory research, and health AI to analyze our corpus of collected articles. We provide more information about our positionality in Section 4.

We began our analysis with the first author critically examining the articles in our core corpus, documenting 1) key concepts within, and recommendations raised, by these articles, 2) weaknesses in the approach or other elements of the work, and 3) open questions and research gaps that the articles pointed to—all as they relate to advancing racial health equity. In our analysis of these articles, we examined and questioned:

- the strengths and weaknesses of the methods used to engage the public in design, and the extent to which the articles evaluated the success of these methods

- the extent to which the work engaged racially minoritized groups, focused on advancing racial equity, and supported reflection on social and structural health determinants
- the extent to which the articles supported design ideation around the positive aspects of a population (e.g., assets and strengths) versus its challenges
- the level of design ideation that was supported in the articles (from high-level strategic planning, to low-level reflection on AI models), and how such ideation was supported or inhibited

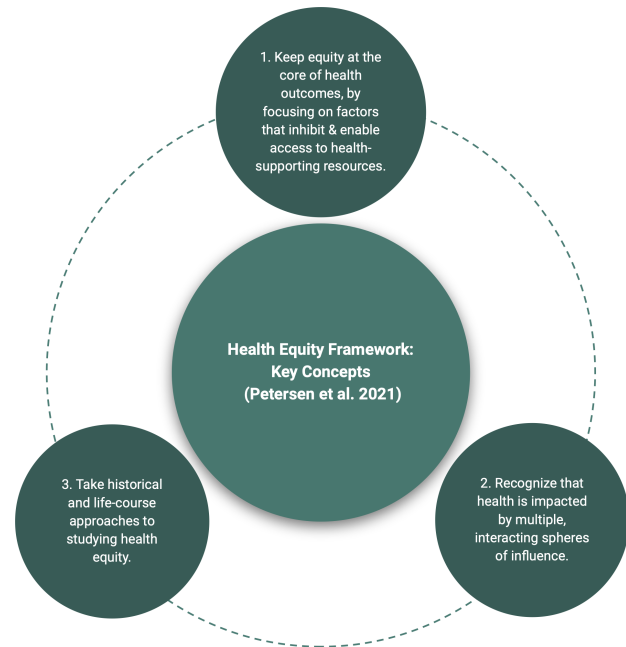
We explored each of these topics, and following a critical review interpretivist methodology [56], we also remained open to inductively surfacing additional observations of relevance to our research questions, documenting these observations as well. This analysis process was further enriched as we repeatedly consulted the broader research literature on participatory AI, considering findings arising in our core corpus in light of this larger participatory AI literature and vice versa. Throughout this process of reviewing the articles and documenting observations, the first author organized these observations into themes representing insights arising across the articles. Our team met repeatedly to discuss and critically examine these themes.

After inductively arriving at an initial set of emergent themes, we sought a conceptual framework that could help to further organize and deepen our analysis. Specifically, we sought a conceptual framework that could attune our attention to the factors that support and inhibit health equity, to help us analyze how well existing participatory AI work has supported racial health equity and how it can more effectively do so in the future. While many behavioral health frameworks exist [76], these frameworks are typically broadly focused on wellbeing without a specific focus on addressing health inequities. We thus considered the smaller body of health equity-focused frameworks.

The Framework for Digital Health Equity [186] is a conceptual tool that shared an overlap in focus with our work, however this framework included a number of concepts that were not directly pertinent to questions, critiques, and considerations that were arising in our review of the participatory health AI literature, and thus a poorer conceptual fit for our current work. Another relevant framework, the Health Disparities framework [5], provides a useful and comprehensive overview of the factors that influence health and that contribute to health disparities. However, the detailed focus of this framework on specific health determinants inhibited our ability to flexibly apply it to the various topics and issues of importance arising in the participatory AI literature.

**3.3.1 Health Equity Framework.** After reviewing relevant frameworks, we selected Peterson et al.'s Health Equity Framework (HEF) [175], and used this conceptual tool to organize and refine our observations and critiques of prior work. As shown in Figure 1, the HEF includes three overarching concepts that describe how the complex interactions people have with their environments shape their health outcomes and ultimately how these interactions can create and inhibit health equity.

Peterson et al. [175] created the HEF through an iterative process that included examining existing frameworks conceptualizing the multilevel influences on health, and synthesizing key concepts



**Figure 1: The Health Equity Framework's three core concepts [175].**

across these frameworks into a single integrated health equity framework, which they further iterated on through interviews with public health, social science, and health equity stakeholders—further establishing the framework's validity and utility. In developing this integrated framework, the researchers' aim was creating a conceptual tool that guides health equity research and practice across diverse disciplines [175]. The HEF's broad applicability across disciplines made it a particularly effective and flexible conceptual tool for us to apply into our more specific use context of participatory health AI research.

We chose the HEF because, more than other frameworks we considered (e.g., [5, 186]), its analytic level of focus and its concepts were well-aligned with the open questions, insights, and shortcomings we were observing through our initial analysis of the literature. In particular, key HEF concepts and arguments of direct relevance to our analysis included the HEF's emphasis on systems of power, the crucial role of social and structural determinants of health and that individual-level interventions alone are insufficient for combating health inequities, and that it is essential to understand how health and health equity are shaped over time.

In summary, we engage the HEF as a flexible conceptual tool to guide our critical review of HCI, health equity, and participatory AI research as it relates to involving the public in the design of more racially equitable health AI tools. Through this analysis, we distill a set of considerations that are crucial for future research that advances racial health equity by engaging racially minoritized communities in the future of health AI.

## 4 Positionality Statement

We find it important to share our positionality as a commitment to reflexivity in HCI work. Our research team is composed of scholars who have conducted several years of research examining how technology can advance health equity. Three authors have each conducted community-engaged research designing health technologies with racially minoritized and otherwise marginalized communities for at least ten years (primarily Black but also Latinx). All authors reside in the U.S.; two identify as Black American, one identifies as White American, and another identifies as Indian American. We bring diverse cultural backgrounds, lived experiences as it relates to the social construction of race, and scholarly expertise regarding racial health equity and health technology design to the examination of the current state of, and future directions for, participatory health AI.

## 5 Participatory AI for Racial Health Equity: Current Research Gaps

Through our analysis, we have identified a set of eight research gaps in prior participatory health AI research that we argue significantly impede progress towards racial health equity. In this section, we highlight these gaps and underscore key considerations, unresolved challenges, and limitations in current research that must be addressed to facilitate advancements in racial health equity through participatory health AI practices.

### 5.1 Addressing the Root Causes of Inequity

This first concept from the HEF emphasizes that health inequities are caused by *upstream determinants of health*, so-called “upstream” because while individual-level factors like health behaviors, attitudes, and self efficacy are more proximal (*downstream*) to health outcomes (e.g., exercise has a direct impact on health), these individual-level factors are shaped by social and structural determinants that operate at a level that is more removed (i.e., “upstream”) from health outcomes [175]. *Social determinants of health* refer to the conditions in which people live, learn, work, and play that impact wellbeing (e.g., neighborhood environments, social and community contexts, access to quality education, economic stability, and access to quality healthcare) [156, 163]. The *structural determinants of health* are social, political, and economic factors that create health inequities by enabling and inhibiting access to social determinants of health (e.g., policies, laws, socioeconomic stratification, cultural norms, racism, and discrimination) [199]. Attempts to reduce inequities by targeting individual level factors alone are ineffective because they neglect to address the larger social and structural forces that shape health behaviors and attitudes.

Recognizing the profound influence of upstream determinants on health and health equity, the HEF emphasizes that interventions must help communities achieve “fair access to resources and opportunities that facilitate positive physical, emotional, and social health, including education, health services, and housing as well as support systems, safe environments, and social capital” [175]. Furthermore, the HEF emphasizes that structural factors such as institutional and interpersonal biases like racism, ableism, homophobia, and classism—and the discrimination that comes from these

biases—create harmful economic, social, and environmental conditions that impede access to resources for wellbeing and increase exposure to harms. In summary, if health AI interventions fail to address upstream factors, they will not support health equity. In this section, we discuss several gaps in prior work that demonstrate how participatory health AI research has largely not addressed upstream determinants of health, nor engaged community-level approaches or been responsive to the prior knowledge held by design participants—efforts that are also essential for addressing upstream drivers of racial health inequities.

**5.1.1 The Upstream Design Ideation Gap.** Through our critical review, the first and most foundational gap we identified is that **participatory health AI work has rarely focused on racial health equity, and has primarily focused on designing for individual level health influences (e.g., as in [10, 11, 133]), with scant focus on addressing the social and structural health determinants that create racial inequities.** While researchers have invited participants to imagine health AI futures (e.g., [8]), we find that prior work has rarely reported scaffolding participant brainstorming around the various ways that racial inequity can manifest in health AI systems. Yet, relying on participants to naturally consider the factors that create racial inequity is likely to prohibit a comprehensive, collaborative exploration of social and structural components of inequity. While these issues may be raised by some participants, for others, considering the structural and social factors that underlie racial health inequities and that can manifest in health technologies may not be topics that they reflect upon typically and thus may not naturally arise in their design ideation. Indeed, while not focused on health, Jäskeläinen et al. found that in their workshops focused on designing creative AI technologies, participants did not naturally consider justice-oriented issues in their design brainstorming until prompted to do so [102]. Crucially, the ramifications of justice-oriented issues not being explored are especially high in a health design context: failure to support the consideration of underlying structural drivers of racial inequity can lead to the design of tools that only serve to worsen the well-being of marginalized groups.

It is thus important to explicitly scaffold design participants’ considerations of social and structural roots of health inequities. For example, Zou and Schiebinger [241] discuss how AI often exacerbates health inequities associated with factors such as race, ethnicity, socioeconomic status, geographic location, sex, and gender, and call for researchers to examine how multiple forms of identity intersect to shape experiences of discrimination and the resulting implications for health AI. While Zou and Schiebinger do not speak to the role that lay individuals can play in such examinations, we argue that participatory design approaches are well-positioned—and vitally needed—to invite members of racially minoritized communities into examinations of these topics, as well as the broader social and structural determinants.

**5.1.2 The Community-Level Approaches Gap.** We argue that putting *communities* at the center of design engagements is one way to expand the focus beyond individual-level factors to the broader, upstream factors that impact health equity—but that **a significant gap**



**in the participatory AI literature is that community-level approaches to design are notably absent.** In the collaborative design of health AI systems, engaged stakeholders have ranged from healthcare providers [190], to AI researchers and scientists, to patients and everyday people [15]. And yet we find that there has been much less focus on design engagements at a *community level* in the health AI space—that is, engaging groups of people with a shared geographic, racial, cultural, or other unifying context and identity [219]. Yet, HCI and public health research has demonstrated the value of such work, including that it can result in work that increases the relevance and value of designed innovations by allowing community members to contribute their particular viewpoints, resources, and strengths, and mitigate technology-induced harms [44, 46, 222].

Centering a community as a unit of analysis in sociotechnical research also helps focus attention on questions about interpersonal, group, and cultural factors that may not be as readily surfaced when the focus is on understanding individual perspectives [44]. For example, community-based participatory researchers acknowledge that individual people are embedded within communities through which they derive socially constructed identities [44]. These identities create strengths and are also associated with societal responses to identities that create inequities. For example, racially minoritized communities experience cultural identities that support resilience and mental health [225, 228] and health inequities as a result of discrimination based on their racial identity [57, 82, 106]. As such, we assert that exploring community identities, perspectives, and experiences can help researchers and designers characterize the underlying social and cultural factors that need to be addressed for health AI to address the upstream roots of health inequities.

While few examples exist of researchers engaging communities in the design of health AI systems that address upstream health determinants, the work of Halperin et al. [84] is a notable exception. These researchers worked with community-based organizations to investigate opportunities for AI to support digital storytelling that addresses housing insecurity [22, 37, 167]. By grounding their work in the priorities of the community organizations, the researchers naturally focused on issues that impact wellbeing on a community level (i.e., housing insecurity).

**5.1.3 The Prior Knowledge Gap.** Another significant limitation of past participatory health AI research is that it has **rarely communicated the extent to which—if at all—participant knowledge and understandings of AI and health were assessed, nor whether—and if so, how—education was provided to participants around these topics.** This gap suggests that people are being asked to ideate AI futures when they may not fully understand the capabilities, limitations, opportunities, or threats that the technology presents, particularly as they relate to the wellbeing of the racially minoritized. Our observation builds upon Diddee et al.'s work, which highlighted that prior NLP projects have rarely helped co-design participants gain relevant background knowledge about the process of creating language technologies [53]. Indeed, we find a similar pattern in health AI research and build upon Diddee et al.'s finding to convey the importance of not only providing participants with relevant background information, but *doing so in a way that is responsive to their prior knowledge*, addressing identified

knowledge gaps and questions that they may have. Furthermore, we highlight that prior health AI work has not only not reported providing design participants with relevant technical knowledge as Diddee et al. highlight [53], but that it has also not discussed exploring and supporting participants' background knowledge as it relates to factors that enable and inhibit health equity.

One example of work that counters this trend is that of Antoniak et al. [8]. In their workshop focused on maternal health NLP design ideation, these researchers describe providing participants with training around LLMs, their use in maternal healthcare, and the ethical concerns and risks that such tools can introduce. Yet, while the authors' reporting of these educational activities is valuable, we argue that future work must provide even more detailed descriptions of to what extent such education is done in a way that helps address relevant gaps in participants' prior knowledge and questions that participants may have around AI, health, and health equity. Such work is necessary to ensure that researchers are creating environments that provide sufficient background knowledge for participants to be able to explore their perspectives on what should and should not be designed in the future, and to be able ideate solutions that address the root causes of inequity. Furthermore, failing to support such knowledge-building is a missed opportunity to enrich the public's understanding around technology that is fundamentally changing so many aspects of society [20].

## 5.2 Contending with Multiple, Interacting Spheres of Influence

The HEF's second concept describes how upstream determinants intersect with individual level determinants to support and inhibit health and also to create health inequities [175]. The HEF lays out four such *spheres of influence*: systems of power, individual factors, physiological pathways, and relationships and networks. We use these concepts to critically review how past work has, as has not, incorporated spheres of influence into participatory health AI research.

**5.2.1 The Power Gap.** The first sphere of influence is *systems of power*, which the HEF describes as “policies, processes, and practices that determine the distribution and access to resources and opportunities needed to be healthy” [175]. With this definition, we see that systems of power are one type of structural determinant of health. Systems of power interact with other health influences to create conditions that are supportive of or that threaten wellbeing. The HEF goes on to discuss how, in part, systems of power harm wellbeing when they create interpersonal and institutionalized biases. Such biases manifest, for example, through racial discrimination in the workplace whereby Black and Latinx adults are paid much less than White adults (institutional racism), and when people experience racial microaggressions from their colleagues (interpersonal racism) [29, 211]. In both institutional and interpersonal discrimination and bias, power is a central factor because it involves the subjugation of one group to another through oppressive actions, interactions, and policies. In addition to, and beyond discrimination, systems of power are central to the creation and dismantling of health inequities because it is these systems (e.g., policies, laws, processes, practices, and institutions) that have the ability to shift the very factors that create health inequities (e.g.,

access to health promoting resources and exposure to factors that harm wellbeing).

As AI begins to permeate all aspects of healthcare, everything from disease detection [128] to drug discovery [174] and treatment decisions [64], there are many stakeholder groups involved in shaping health AI: government agencies seeking to regulate AI [157, 173], corporate entities who stand to profit from AI and face market pressures to innovate quickly [94], AI developers, designers, and researchers who also face pressure to publish and release products quickly [40], and journalists who shape conversations around and perceptions of AI [59, 67, 111]. In the context of health, the players also include healthcare providers and systems, pharmaceutical companies, and health insurance providers—entities that deliver, utilize, and fund advancements in AI to reshape how medical care is provided [103, 127, 216]. And lastly patients [148, 209] and everyday people are arguably *the* central stakeholder because it is their data that fuels AI models and applications, and it is this stakeholder group that most health AI systems are ultimately meant to serve.

Across these varied stakeholders, power is not evenly distributed, and interests often conflict [194]. The profit and efficiency motives of healthcare organizations may stand at odds with patients concerned that these tools are being taken up too quickly without a full consideration of their risks [212, 217]. Understanding these political realities and tensions is essential for ideating health AI futures. There are power-related questions to consider at each phase of the health AI design and deployment process. For example, who determines AI priorities, objectives, and implementation timelines and how are these decisions made? Who owns the data driving health AI tools, and how will people gain or lose decision-making power over that data? How will the AI systems be relied upon in healthcare decisions? And yet, **the next research gap that we find is that prior participatory AI research rarely describes if, and how, the design methods used help study participants to reflect on how these political considerations might shape their preferences for and use of health AI systems.** This is a significant shortcoming in prior work because without understanding this political context, participants are hindered from envisioning systems that respond to and mitigate the constraints, problems, and opportunities that are introduced by the complex web of actors who shape the AI landscape.

**5.2.2 The Flourishing Gap.** In concert with systems of power, the HEF emphasizes that health is shaped by an interplay of more downstream health determinants, including individual factors (e.g., behaviors and attitudes that people develop in response to their economic, social, and environmental conditions), physiological pathways (i.e., physical, biological, cognitive, and psychological abilities), and relationships and social networks. These factors impact one another and are also impacted by social and structural health determinants. A key question then is how can health AI tools be created to help people achieve their highest level of wellbeing amidst these varied influences on health?

This question reflects the idea of flourishing, a multidimensional concept that helps us see beyond a more typical focus on wellbeing as achieving physical and mental health [220]. VanderWeele et al. define flourishing as being comprised of six wellbeing dimensions

that represent thriving in life [220, 221]: life satisfaction and happiness, virtue and character, purpose and meaning in life, material and financial security, close social relationships, and mental and physical health [220, 221].

Flourishing has gained attention within health and medicine in an attempt to broaden the field's appreciation for dimensions of wellbeing beyond simply preventing and managing disease [221]. In parallel, HCI scholars have advocated for a design focus on flourishing that goes beyond creating tools that sustain life and fix health problems [210], to honoring other valued facets of humanity—values, beliefs, and strengths such as enjoyment, rest, and cultural heritage [78, 81, 172]. Yet, our analysis highlights a lack of participatory AI research in this space: **while health AI innovation and design has focused on topics such as disease detection and predicting the onset of health problems [49], there has been little work driven by the ideal of flourishing.** In the context of health equity, there is often a focus on reducing the disproportionately high prevalence of disease burden in racially minoritized communities [145], which is essential. However, to achieve racial health equity—which involves racially minoritized groups achieving their *highest* level of holistic wellbeing—the ambition of participatory health AI must be even greater than this, recognizing the right and desire of marginalized communities to not only survive, but also to thrive.

**5.2.3 The Emotion Gap.** In addition to designing for flourishing, through our review of prior work we find that health AI can be more fully responsive to the multidimensionality of humanity by going beyond a focus on rationalism—something that has largely driven health technology and AI innovations to date [23, 130]. Rationalism as a field of thought, way of knowing, and motivation for design prioritizes quantification of experience, objective health measures, and tends to discount or ignore emotion as an important part of wellbeing [23, 130]. Rationalism underpins self-monitoring innovations that have dominated digital health research and innovation [130]. In these systems, we see the creation of devices and applications that allow people to quantify their experiences (e.g., by measuring physical activity levels) and bodies (e.g., by visualizing blood glucose levels) to drive self reflection, behavior change, and analysis. While these advances are fueling breakthroughs in healthcare and have helped give more control to patients and consumers managing their own wellbeing, these advances represent but one way of approaching the creation of digital health platforms. Researchers have also offered alternative approaches that present a different set of values and attune our focus to the richness of humanity beyond reducing our health-related experiences to objective quantification [130, 131].

The HEF describes how, to advance health equity, it is essential to understand people's health-related experiences, including how individuals respond to their economic, social, and environmental conditions. These responses—be they behaviors, attitudes, or the development of skills—can support health or intensify inequities [175]. Accordingly, we argue that participatory AI research should examine opportunities and challenges for AI to facilitate health-supportive responses to one's environment.

Specifically, we argue that, to achieve racial health equity, there is a need for research that addresses the *Emotion Gap*—**the need**



**for more participatory AI research that goes beyond a focus on rationalism to examine 1) the *emotional* responses that racially minoritized groups have to their economic, social, and environmental conditions, 2) how those responses impact wellbeing, and 3) implications for health AI.** Through such work there is opportunity to expand the HEF's individual factors concept to include a fuller picture of how people react to their circumstances and the implications for wellbeing. Indeed, prior work has shown how emotions impact wellbeing, and that supporting positive human emotions is key to addressing health inequities [2, 168, 176]. Additionally, emotion is particularly salient for participatory health AI work as emotion plays a central role in how we understand and experience the world, and research has shown that accounting for emotion is essential for creating digital technologies that people desire to use and that support them effectively [54, 69, 90, 134]. As such, beyond supporting the design of AI tools that enable *tasks* like diagnosis, prediction, and risk assessment, health AI participatory design work should also contend with the human emotions that are a central part of health journeys, health-care, and health promotion. Lupton et al. [132] write about the importance of studying how health-related activities are “embodied and suffused with feeling.” Building upon this insight, we stress here the importance of understanding the affective dimensions of participatory design participants’ a) health-related experiences and b) perspectives on future systems.

To create positive user experiences with technology, we must identify the emotions people have regarding the experiences our technologies will mediate, and how technology can maximize positive emotional responses when engaging in those activities with and through our technologies [134]. In the context of health equity and AI, one key emotional response that has been under-explored is how people feel about racial bias as it relates to health and implications for design. For example, participants might feel *frustrated* by racial discrimination in the healthcare system [48], *fearful* of mistreatment by police due to their race [33], or *motivated* to address limited healthy food options in their neighborhoods due to racial bias in grocery store representation in communities of color [141, 170, 233]. Identifying these emotions enables design research to not only surface problems, but also understand why addressing those problems is important for the communities at hand, and in turn, design more effective solutions.

Also under-examined is how racially minoritized groups believe emotion should, and should not, be represented in health AI—from the ways that AI models human emotion, to whether or not and how emotions like empathy are expressed by AI tools. Such questions are critically important given that racially minoritized populations consistently report increased negative affective experiences during healthcare encounters, including being disrespected, and that how they feel is dismissed or even disbelieved by their providers [27, 35]. For example, Black adults’ pain is more underestimated, disbelieved, and untreated as compared to White adults [14, 27, 96] as racist beliefs about how Black populations experience pain persist in the medical field [96, 203], and healthcare providers extend more empathy towards the pain of White patients than that of Black patients [57].

**5.2.4 The Relationalism Gap.** Emotional wellbeing is supported in part through our relationships, and the HEF further describes the multifaceted ways that social networks support health equity, for example, through social support that encourages healthy behaviors and mitigates “the social disadvantage produced by systems of power”. Relationships can also inhibit health equity through factors like unhealthy social pressures, discrimination, and stigma that harm health [175]. Indeed, decades of research demonstrate the powerful role that social networks, social support, social integration, and social influence have on wellbeing [41, 196]. Given the vital role that social relationships play in supporting health equity, AI system design must include a focus on relationships. And yet, the influence of rationalism on digital health can again be seen in the proliferation of systems that support the wellbeing of *individual* users, rather than considering how *social* interactions and groupings are relevant for health [201]. In particular, we argue that a turn to rationalism can be seen in much of the work being done in health AI because the lauding of precision medicine is, at its core, a celebration of the ability to customize treatments, diagnoses, and behavioral change support to the individual [75, 109]. With this point, we characterize the *Relationalism Gap* in prior participatory AI research: we find that **there has been limited work examining how relationalism can be a key asset in supporting AI design work that advances racial health equity.**

Of relevance, recent AI scholarship on relationalism has called attention to the need to investigate social factors in the design of these systems [6, 23]. Relationalism as an epistemological alternative to rationalism rejects an individualistic focus by highlighting how human existence and wellbeing is supported through connections to others [23]. We offer that embracing a focus on relationalism in participatory health AI research would first entail prioritizing empirical methods that value the interconnectedness of participants. And yet, we found that of the nine papers in our corpus that reported conducting human subjects empirical research addressing health equity topics, only two ([8, 12]) reported using methods that brought participants together in group settings to collectively consider possible futures for health AI (the remainder chose, for example, individual interviews to gather participant insights). Secondly, a participatory health AI focus on relationalism will also mean exploring collectivist design concepts rather than solely focusing on the individualistic leanings prevalent in digital health research [171, 201]. As equity-focused participatory health AI work is just beginning to emerge, we have not yet seen a robust body of work that comprehensively examines the ways that health AI tools might be designed to engage the power that social networks have to support racial health equity—and how these tools might help mitigate the ways that social relationships can hinder health equity.

### 5.3 Taking Historical and Life-Course Perspectives

The final concept in the HEF is the necessity of understanding how health and health equity are shaped over time [175]. As people move through different stages of their lives, the systems that impact their wellbeing change. For example, the family environment plays a major role in a young child’s wellbeing, and as we age,

other environments become more salient, such as workplace environments. This concept also emphasizes how health inequities are caused by cumulative exposure to health threats over time. Seminal research has established, for example, the *weathering* effect—the way cumulative exposure to discrimination, adversity, and political marginalization wears on racially marginalized communities' bodies at a psychological level but also physiologically—causing deterioration that contributes to racial health inequities [68, 74]. Phenomena like weathering reflect the HEF's emphasis on moving beyond point-in-time examinations of wellbeing, to understanding the broader impacts of historical contexts and life stages on health and health inequities. This brings us to the final gap that arose from our critical review.

**5.3.1 The Longitudinal Community-Engaged Design Gap.** Most digital health equity and human-centered AI research has only engaged participants for a single study session [8, 19, 51, 120, 201, 214, 215]. On one hand, brief design engagements seem to make pragmatic sense given how rapidly AI systems are being created—there is a sense of urgency to quickly gather input to drive the swift creation of new systems. And yet, brief design engagements are insufficient to ensure that systems are not only designed for majority populations but also those on the margins. Eliciting and acting upon varied population needs and perspectives requires time.

In the context of racial health equity, we argue that there is a **need for more research that engages in repeat, longitudinal design engagements with communities, to mitigate the ways that brief design engagements inhibit progress towards racial health equity**. First, repeated design engagements support exploring participants' nuanced experiences regarding race and wellbeing—including the historical roots of those experiences (e.g., legacies of cultural resilience and experiences of discrimination in communities) and the implications of those experiences for AI design.

Additionally, longitudinal design work supports collaborative design thinking as health AI models and applications evolve. Indeed, it is precisely because of the rapid pace of health AI innovation—and the repeated evidence of racial inequities in such "innovations" [151, 153, 191]—that longitudinal engagement is critical. Longitudinal design efforts are also needed given the evolving conversations regarding the societal implications of AI and efforts to establish regulation and practices that shape its creation, use, and impact on populations [79, 100, 121, 173]. Repeated interactions with participants creates space for communities to engage in dialogue regarding these evolving topics, and also to revisit their perspectives regarding health AI, which are likely to evolve alongside the ever-changing technological, societal, and regulatory landscape.

Lastly, a single session may leave insufficient time to assess existing AI and health equity knowledge and create responsive co-learning experiences that bring participants to a place of concept fluency that supports meaningful participation. Engaging communities longitudinally in design can build community expertise around these topics as well as design thinking processes, helping communities to iteratively ideate around progressively complex topics. This benefit of longitudinal engagement can help to address potential concerns, discussed above, regarding the time required to engage in longitudinal design efforts. As community members become

more experienced with design ideation, this may enable more efficient design work, making them feasible even within tight project timelines.

## 6 Participatory AI Strategies for Advancing Racial Health Equity

Our analysis of prior work yielded a set of eight research gaps illuminating key considerations, open questions, and limitations in prior research that are essential to address if future participatory health AI efforts are to advance racial equity. Prior work has critiqued the field of participatory AI broadly, for example, questioning how we can meaningfully engage the public in creating AI [24], highlighting the shortcoming of "time-limited engagements" that fail to engage stakeholders in design longitudinally [20], and warning against participatory AI work that extractive and that exploits communities [192, 193]. This important body of work has laid out several issues of relevance for any participatory AI project; yet it does not explore these and other key questions that arise when designing health-related AI efforts and when attempting to conduct work that addresses racial injustice. The gaps that we lay out in this paper take the vitally-needed next step in advancing participatory health AI research that focuses on racial equity by 1) discussing the new concerns, questions, and opportunities that arise when considering previously-raised human-centered AI critiques in a racial health equity context (e.g., the Relationalism and Longitudinal Community-Engaged Design Gaps that we surface), and 2) introducing additional issues that have received scant attention in the participatory AI literature and elucidating these key issues in a racial health equity context (e.g., The Upstream Design Ideation, Prior Knowledge, Emotion, and Flourishing Gaps).

Indeed, beyond issues common to any participatory AI effort, there are distinct challenges, complexities, and concerns that arise in a racial health equity domain context, such as the increased sensitivity of data in health systems and models, and the heightened need to ensure health AI tools are safe and fair, given that if these tools fail to work effectively and justly, the stakes are much higher than in other domains. Health AI tools stand to have potentially life or death implications, impacting the bodily and mental wellbeing of populations. Furthermore, healthcare and health AI tools have a history of disenfranchizing racially minoritized populations by providing inferior care [96, 153], meaning that any attempts to introduce technology into a health context require additional scrutiny to ensure they are fairly and equitably serving the racially minoritized. These unique aspects of health AI necessitate deliberate examinations of the particular steps that must be taken when engaging the public in the design of health AI—steps that go beyond general participatory AI principles—to ensure that design work is contributing to racial health equity.

Participatory AI research has produced a growing number of frameworks and toolkits, including those that conceptualize different forms of stakeholder participation [51], AI governance [126], values and principles for the creation and evaluation of AI [50], and broad guidance for engaging the public in AI design and deliberation [28, 114]. While these resources provide valuable guidance for field of participatory AI generally, they do not enable researchers to answer the question of how communities can be engaged to ideate

health AI futures *that explicitly combat racial health inequities and scenarios where not pursuing health AI innovation may be the most equitable decision*. Through our analysis of key gaps in prior work we are well-positioned to address this limitation of prior work.

Indeed, critical literature review methodologies utilize an in-depth analytic synthesis of prior work to produce as an output recommendations that help focus and direct future work [166]. Accordingly, we present a set of participatory AI strategies that we encourage future work to take up, test, refine, and expand upon. Each of these strategies is a way of responding to the gaps we have identified in prior work. The strategies were derived from our critical analysis of prior work, and they represent grounded recommendations that can serve as a starting point for catalyzing future work focused on the participatory design of more racially equitable AI futures—an area of research that is woefully understudied yet vitally needed. It will be particularly important for future work to test and evaluate these recommendations with racially minoritized communities, to explore how they can be further refined and expanded upon.

In this section, we present eight strategies for engaging lay communities in the design of AI-enabled health technologies that directly address racial inequities. The connection between these strategies and the gaps identified through our analysis is shown in Table 1. A key facet of these strategies is an appreciation that at any point, AI or technology more broadly may be rejected by a community as an effective tool for addressing their health priorities.

## 6.1 Strategy 1: Prioritize Community-Centered Design to Support Upstream Design Ideation

To address the Upstream Design Ideation Gap and the Community-Level Approaches Gap, we provide a perspective for how **future work can more effectively engage in community-centered health AI design, and how doing so can support upstream design ideation that advances health equity**.

While engaging communities is an important way of addressing the upstream roots of health inequities, *how to effectively and equitably engage communities in the design of health AI systems* has remained an open question. Prior work has examined how “participation” is framed within sociotechnical AI research broadly [20, 24, 194], but has rarely engaged community entities [51, 53], or examined the specific opportunities and challenges of community-engaged participation in a health AI context. Addressing these shortcomings, we discuss our first strategy for catalyzing participatory AI efforts that advance racial health equity.

Designing health AI systems with and for *communities* is different from designing these tools with and for *individuals*. Community-centered design would not only consider how an individual experiences a health issue or how they see a technology impacting their own life, but also the impacts of a health issue on a community, and the implications of technology at that scope. One challenge is that when we invite members of a community into a design process, we run the risk of asking them to speak on behalf of their broader community—a process of tokenism that is problematic, unrealistic, and potentially harmful [51, 83, 154]. This begs the question, how can we effectively counter tokenization in participatory health AI

research? Prior work on community engagement in medical research offers several recommendations for countering tokenization that can guide future participatory AI work [47, 83].

First, it is essential that researchers not use convenience samples when recruiting for participatory AI studies. Instead, researchers should use purposeful and stratified sampling approaches, to ensure that participants represent varied viewpoints and experiences within a community. When designing health AI tools aimed at addressing inequities within a specific racial group, for example, the participatory work should then invite participants from diverse genders, socioeconomic statuses, disability statuses, sexual orientations, and other relevant identities within the racial population to ensure those varied perspectives are represented. This practice is especially important when addressing racial bias, as research shows that experiences of racism vary by subgroup [7], and the canonical work led by Patricia Hill Collins, bell hooks, and other Black feminist scholars highlights the essential way in which intersectional identity (e.g., across race, gender, and class) shapes experience [36, 43, 97].

Second, to be active contributors during design work, participants need to be given adequate background knowledge regarding the topics being explored, and concepts should be communicated accessibly and without jargon [83]. Failure to adhere to these principles results in tokenization because without sufficient knowledge, community members are not able to meaningfully engage nor contribute their expertise to shape the resulting health interventions being created. These considerations highlight the need to ensure that participants have an understanding of AI concepts, including how these concepts relate to health promotion and health management. The general public often lacks a deep understanding of what AI is, how it is created, its capabilities, how they are already using it in their daily lives, and the potential it presents for harm [63, 116, 144]. This limited background knowledge can thus constrain the public’s capacity to make informed decisions about, and articulate preferences for, future AI systems [53].

## 6.2 Strategy 2: Support Co-learning to Counter Tokenism & Ground Meaningful Participation in Design

Indeed, addressing the need to attend to the prior knowledge that participants bring to design engagements, we posit that **supporting collaborative learning (co-learning) is a critical approach to addressing the Prior Knowledge Gap in previous research, as it is a practice that can help researchers counter tokenism by ensuring participants and researchers have sufficient shared knowledge to meaningfully collaborate in design**. After assessing a community’s prior knowledge as it relates to health equity and AI, it is important to collaboratively learn with communities around what we call *axes of equity*—factors that directly impact health equity and are important for scaffolding AI design thinking that supports health equity. We have discussed these topics throughout our discussion of research gaps in Section 5, and the axes of equity are visualized in Figure 2. By *co-learning* we refer to a dialogical experience in which researchers introduce concepts to community members and vice versa. In this co-learning, researchers and community members work together to reflect upon and revise

**Table 1: Participatory AI for Racial Health Equity: Gaps, Strategies & Associated Health Equity Framework (HEF) Concepts.** This table lists the research gaps we identified in our review of prior work. For each set of gaps we also list the associated HEF concept that highlights the health equity principles that prior participatory AI research has largely not addressed. (See Figure 1 for a full description of each HEF concept.) Lastly, we list the corresponding strategies we encourage future work to use to address each gap.

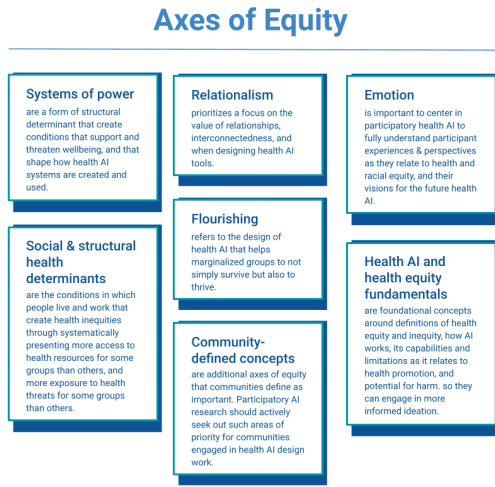
HEF Concept	Current Gaps in Participatory Health AI Research	Strategies for Future Work
HEF Concept 1	Upstream Design Ideation Gap	<b>Strategy 1:</b> Prioritize Community-Centered Design to Support Upstream Design
	Community-Level Approaches Gap	<b>Strategy 3:</b> Support Community Engagement from High to Low-Levels of Design
HEF Concept 2	Prior Knowledge Gap	<b>Strategy 2:</b> Support Co-learning to Counter Tokenism & Ground Meaningful Participation in Design
	Power Gap	<b>Strategy 4:</b> Scaffold Design Thinking Around Issues of Power in Health AI Decision Making, Innovation & Use
	Flourishing Gap	<b>Strategy 5:</b> Support Design Thinking that Goes Beyond Survival to Cultivating Flourishing
	Emotion Gap	<b>Strategy 6:</b> Engage Communities in Ideating the Opportunities and Limits of Designing for Emotion in Health AI
	Relationalism Gap	<b>Strategy 7:</b> Embrace Relationalism as a Driving Concept in Design Efforts
HEF Concept 3	Longitudinal Community-Engaged Design Gap	<b>Strategy 8:</b> Engage Communities in Meaningful Longitudinal Design, on Their Terms

understandings, prioritize concepts most needing to be addressed in design efforts, and develop new concepts that require attention in design efforts. Co-learning is important to address knowledge gaps in the research team and community, and helps researchers better understand what matters to communities.

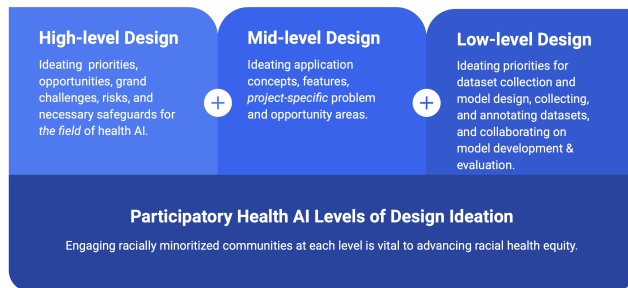
By emphasizing a co-learning approach, we build upon the community-based research principle of conducting research that not only helps the research team learn about the communities being studied, but that research should also help communities build their own knowledge [218]. Furthermore, a co-learning approach emphasizes that participants have essential lived experience to share and potentially occupational or educational expertise on the topic to share as well [20]. Co-learning enables the researcher and community member to explore topics of relevance together, to build a shared understanding that is richer, and informative for scaffolding 1) participants' continued participation in the design work and 2) researchers' continued analysis of opportunities for health AI to

meet community values, needs, and priorities. Given that racially minoritized groups are rarely engaged in the design of health AI systems, doing this initial work is important for ensuring their perspectives are driving design efforts in a fundamental way—down to questioning, refining, and exploring the very definitions and framings for concepts whose meanings may be taken for granted by health AI researchers and practitioners.

We recommend that researchers not only report how, and to what extent, they assessed participants' background knowledge of AI and relevant health information (e.g., [189, 213, 217]), but also how their research facilitated co-learning, and participants' attitudes towards the efficacy of that co-learning (e.g., survey questions that assess participants' attitudes regarding the amount and value of knowledge they gained, how well they were respected and enjoyed the learning activities, etc.). Indeed, once co-learning has yielded insights into opportunities for enriching community and researcher knowledge around health equity and AI concepts, researchers must



**Figure 2: Axes of equity are factors critical to scaffolding AI design thinking in a way that supports racial health equity. The concepts reflected in these axes were introduced throughout Section 5’s discussion of gaps in prior work. We further discuss these concepts across the participatory AI strategies for racial health equity presented in Section 6. For example, Strategies 2 and 3 describe the importance of supporting co-learning and design thinking with participants that is focused on each of these axes of equity (Sections 6.2 and 6.3).**



**Figure 3: Three levels of design ideation for participatory health AI research, as discussed in Strategy 3 (Section 6.3).**

adapt and develop methods that address learning opportunities and project aims (which, to support community empowerment, should be co-established together with community members [226]). Future work must carefully consider how to adapt and create new methods to support co-learning around the axes of equity shown in Figure 2.

### 6.3 Strategy 3: Support Community Engagement from High to Low-Levels of Design

In addition to mitigating tokenization through strategies like co-learning, meaningful community-centered design can be supported

by ensuring that communities are engaged in all phases of AI development [20, 47]. We take a different approach to classifying and highlighting opportunities for community participation in design than in prior work [20, 51, 194]; we organize participation opportunities in terms of the *levels* of design thinking that participatory health AI projects can invite: *low-level design* of datasets and models [20, 47], *mid-level design* of application concepts and features, and articulation of project-specific aims the technology should address [103, 223], and *high-level design* that goes beyond articulating aims for a specific project [20, 47], to brainstorming broader priorities, opportunities, grand challenges, risks, and necessary safeguards for the field of health AI [100, 155] (Figure 3). As a means of addressing the Upstream Ideation and Community Level Approaches gaps, this classification strategy—supporting community engagement from high to low-levels of design—supports consideration of the particular opportunities, considerations, and challenges that arise with each category of design engagement.

For example, while all design ideation levels are essential, Birhane et al. [24] note a lack participation in higher-level design considerations as a limitation of prior participatory AI work broadly, and caution that participatory engagements that focus solely on lower-level design ideation leave “little room (if at all any) for co-exploring, co-creating, and/or negotiating the larger objectives, reflections, and implication of AI systems.” In a health AI context, there are several high-level topics that would benefit from community input, such as how to ensure equitable health data governance and just forms of health AI regulation. Each of these topics are being actively investigated by technologists, policy and healthcare experts, and researchers [60, 79, 100, 139, 157]. Yet marginalized communities also have much insight to offer into these topics based on their lived experiences, which can drive advocacy around AI policies and strategic direction planning by researchers, companies, healthcare organizations, and other stakeholder groups [100, 121]. To ensure a comprehensive participatory AI research agenda that produces health AI innovations that address inequities, it is crucial that future work explore how to engage community members in low-level and mid-level design ideation, but also the crucial and understudied area of high-level design ideation. Additional examples of design thinking at each level are included in Appendix B.

In addition to failing to support health AI design ideation, we find that prior AI research has rarely engaged participants in considering upstream roots of health inequities across each design ideation level. This shortcoming means the health AI tools built based on such participatory AI work are poised to be less effective at actually reducing health inequities than if participant input had been sought with regard to these topics. There is a need for research that scaffolds design thinking that addresses upstream factors in low-level, mid-level, and high-level participatory AI projects.

Furthermore, health AI is being created, used, and regulated in a variety of contexts (e.g., academia, industry, healthcare systems, health insurance companies, governments, and community organizations) [4, 39, 49, 65, 93, 108, 157, 158, 184]. To ensure marginalized communities’ views are driving health AI innovation and practices, work must engage communities in design thinking in each of these contexts. Engaging communities in AI ideation in each of these

sectors will be essential for ensuring community members are connected to individuals who have the power to realize their visions for the future.

At each level of design, research methods should support design thinking around the axes of equity (Figure 2). Prior work offers some starting points for research that adapts and develops methods that enable such design explorations. For example, researchers have conveyed the value of grounding design efforts with marginalized groups in frameworks such as Black feminism and Afrofuturism. These frameworks support reflection upon futures free of oppression, and that grapple with issues around race and identity [88]. Employing such frameworks can also help the racially minoritized to see themselves as part of the design futures being conceptualized [88]. More broadly, research has explored creating methods to scaffold design ideation in marginalized communities [124]. For example, in their work with Black youth, Solyst et al. [200] showed how framing participatory AI spaces as informal learning environments enabled them to engage participants' prior knowledge and interests to create culturally responsive design environments. This research offers approaches that can be used and adapted to support health AI co-learning and design ideation that focuses on the axes of equity.

#### 6.4 Strategy 4: Scaffold Design Thinking Around Issues of Power in Health AI Decision Making, Innovation & Use

One axis of equity that we discussed previously is power; in Section 5, we denoted the Power Gap as a key limitation in prior work, whereby little work has supported health AI design ideation that focuses on issues of power. And yet, while the health AI stakeholder landscape is complex, lay people are quite adept at considering how issues of power manifest in their lives and in the world, and engaging in design thinking that is responsive to that reality [61, 137]. For example, To et al. [211] used the narrative episode interview method to provide racially minoritized individuals the space and autonomy to share experiences of racism and opportunities and challenges they saw for digital social support amidst experiences of racism. Bray et al. [31] created the Building Utopia toolkit, which supports community-led design thinking around topics like establishing what “freedom” means for a community and how it can be achieved. Integrating methods like these can help participants describe their experiences with systems of power that impact their wellbeing and brainstorm desired futures.

However, to help participants bridge the gap from present to future, **future work must use, adapt, and develop design methods that help participants consider how power is wielded to inhibit wellbeing in racially minoritized communities, the current structures of control that shape health AI decision making, innovation, and use, and ways that communities have harnessed power to effect positive change.** Such approaches are necessary to support generative design thinking that is responsive to political realities. For example, prior work in HCI has engaged concepts from Black feminist theory that unpack how Black communities experience interlocking forms of oppression as a result of multiple marginalized identities (e.g., due to their race, gender, class, disability, or other social category) [42, 62, 182, 183]. Such

work can be adapted to more deeply support participants' thinking around the ways that oppression manifests in a health and an AI context, and the limitations and opportunities for AI systems to push back on those forces, for example, by leveraging the collective power of community activism and resistance.

#### 6.5 Strategy 5: Support Design Thinking that Goes Beyond Survival to Cultivating Flourishing

In addition to power, another axis of equity (Figure 2) that we have discussed is flourishing. **To address the Flourishing gap that we observe in prior work, participatory health AI research must aspire to co-generate with communities tools that do more than prevent and manage disease; such work should also activate and advance marginalized groups' ability to flourish.** For example, low-level design ideation could scaffold reflection on how datasets can be collected and annotated to reflect the virtues inherent within a community (going beyond data like their medical records or population health statistics like disease prevalence)—and how doing so might be a way to affirm the dignity of racially minoritized communities often studied from a deficit perspective. Mid-level design research could explore how AI applications can help support a sense of material and financial security in racially minoritized populations where structural racism has resulted in lower levels of wealth and housing security (e.g., through tools that enable new, accessible, and rewarding forms of work that generate increased income streams) [26, 52]. High-level design ideation could enable communities to create AI principles that guide companies, researchers, and developers to create AI systems that go beyond disease prevention to also supporting a sense of purpose before being made available for public use (e.g., establishing metrics to evaluate if designed tools meet this objective). A participatory AI context allows us to understand how communities define and view flourishing, the extent to which they see AI as a technology that can support flourishing, and what may stand in the way of flourishing.

#### 6.6 Strategy 6: Engage Communities in Ideating the Opportunities and Limits of Designing for Emotion in Health AI

Our next strategy addresses the Emotion Gap. As research increasingly explores the design of AI systems that intentionally infer, analyze, and interact with emotions [58, 179], we argue that **a key task for participatory AI research will be scaffolding marginalized communities' reflections on the extent to which they desire AI systems that mediate their emotions in health-related experiences, how such tools could address and exacerbate harms, and ways to mitigate such harms.** Just as Pyle et al. [179] explored marginalized groups' perspectives on AI mediating their emotions in job interviews, there is also a particular need to examine racially minoritized communities' perspectives on how AI should and should not mediate their emotions in health experiences. AI is increasingly being used in the context of health experiences where emotion plays a central role, such as patient communication with their healthcare team and the assessment and management of pain levels [188, 238]. And yet, racially minoritized groups such as

Black and Latinx populations have experienced significant harms in each of these healthcare areas, and more broadly, persistent threats to their emotional wellbeing in healthcare, neighborhood, workplace, and other environments [35, 198, 237]. It is thus essential that participatory research examine how AI tools can be designed to respectfully, accurately, and sensitively mediate emotional experiences, support emotional wellbeing in racially marginalized individuals, and establish contexts where *not* using AI at all may be the more effective path towards supporting emotional health in marginalized groups.

## 6.7 Strategy 7: Embrace Relationalism as a Driving Concept in Design Efforts

In addition to the Emotion Gap, our discussion of the limits of rationalism highlighted the Relationalism Gap. **To address the Relationalism Gap, we encourage future work that prioritizes a relational approach in participatory health AI study design and design ideation.** First, group design workshops, autoethnographic sister circles (which support collaborative storytelling about experiences and trauma), embedding design work within community settings, and other collectivistic approaches can be prioritized to emphasize design sessions as sites of healing, and opportunities to more deeply understand one's perspectives through interactions with and learning about others [23, 85, 87, 180]. There is a distinct value in group design settings that help participants collaboratively make sense of health inequities and the opportunities and limits of AI to respond to these inequities. Furthermore, there is much opportunity for HCI research that examines how people's perspectives on AI, health, and equity are shaped and evolve through their interactions with other participants. It is rare to see reports of how participants' perspectives evolve as they explore topics together with their fellow study participants. By studying such evolution, there is an opportunity to learn how to better support collaborative learning, sensemaking, and design thinking.

In terms of design ideation, as researchers, designers, and community members engage relationalism as a design orientation, this will necessitate exploring opportunities, risks, and challenges introduced by collectivist design concepts. For example, at a low level, participatory design can help participants consider how community datasets can be created that drive models characterizing the latent opportunities for social support within a neighborhood. Indeed, prior work has demonstrated how vital social support is for reducing racial health inequities, by enabling healthy behaviors and emotional wellbeing in racially minoritized populations who face increased barriers to physical and emotional wellbeing [89, 165, 234]. Mid-level design ideation could then build upon such work, scaffolding ideas for AI system features that catalyze relationship building and social support amongst community members, and proactively investigating how such tools might unintentionally harm relationships. Such low- and mid-level design efforts are an example of how embracing relationalism in design may also help address the Emotion Gap, given that relationships have a direct impact on emotional wellbeing, for example through support for healthy coping behaviors and mitigation of racial and non-racial stress [89, 231, 234]. For high level design ideation, the importance

of community-engaged data governance is increasingly being recognized, particularly in the context of marginalized populations [38, 139]. While work in this area is starting to emerge [38, 139], particularly as theorized by legal, policy, ethics, and computer science researchers [38, 138, 139], there has been scant research that invites the perspectives of the racially minoritized as to how community data governance approaches should be designed. In addition to the need for such work, there is further opportunity to explore broader benefits of community-led data governance—such as strengthening community cohesion by building bonds, trust, and a sense of solidarity amongst community members.

## 6.8 Strategy 8: Engage Communities in Meaningful Longitudinal Design, on Their Terms

The strategies we have discussed in this section would each benefit from longitudinal design efforts, and yet in Section 5 we highlight the Longitudinal Community-Engaged Design gap that exists in prior participatory health AI research. Furthermore, while designing AI tools that advance social justice requires long-term engagements, this work is inherently challenging, requiring greater investments of temporal, human, and financial resources [47, 51, 194, 205]. Given the paucity of long-term participatory AI research and the inherent challenges with such work, **we discuss ways of catalyzing longitudinal, community-engaged participatory AI efforts, particularly in racial health equity contexts.**

First, longitudinal engagements are especially challenging in corporate settings where capitalist motives prioritize efficiency and where there has been a history of extractive community interactions [194]. Yet, it is in such contexts that much of the AI innovation is happening, and thus where there is a particular need for such participation. Creating standing *community design collaboratives*—community members who are recruited into an community advisory board that engages in participatory design work over time—can facilitate these engagements. Such collaboratives can build their knowledge of AI opportunities and challenges as they engage in design activities over repeated interactions that might span months, or even years. While such engagements may appear too time, human resource, and cost-prohibitive [194], a fundamental principal of HCI is that it is less expensive to solicit stakeholder input on design early and iteratively because they can help mitigate issues that will be even more expensive to fix later on [149].

Additionally, it is important to explore organizational and community structures, settings, and rhythms that can enable longitudinal design work. In our review of prior work, we found that of the few participatory AI studies that engaged racially marginalized groups in repeat design efforts, two were conducted with students in structured environments that lend themselves to such multi-session engagement (e.g., afterschool programs and summer camps) [182, 200]. It is thus important for future work to explore what community infrastructures can scaffold long-term design engagements. For example, churches and community centers are places that local residents come back to again and again; barber shops and salons also see patrons visiting with regular rhythms. Public health researchers have long engaged such community entities for health equity interventions [226], and these community settings may also



be promising locations to support longitudinal design efforts. For example, recent work engaged Black church communities in the design of conversational agents for health promotion—partnering with churches to conduct a series of design workshops over multiple years [159, 160, 202]. Such longitudinal partnerships require sustained commitment and effort to maintain, but are essential for supporting long-term design work in community settings.

Finally, research is needed to create methods and research instruments that support longitudinal evaluations throughout all phases of health AI design and development. While some measures exist to assess topics such as AI literacy [21], there are few measures that evaluate community knowledge around health equity, and we know of no research instruments that support evaluating to what extent AI design efforts are supporting health equity. Furthermore, across these areas of assessment there is little work tailored to exploring the perspectives of racially minoritized populations, who have unique insights to offer, for example, given their cultural heritage and experiences with societal oppression. Four important areas of assessment for future research to consider include:

- (1) Community-held knowledge: before assuming what a community does or does not know about AI, equity, and health, it is crucial to conduct empirical work that studies this prior knowledge and how that knowledge evolves throughout design processes.
- (2) Design processes: future work should evaluate the effectiveness of health AI design efforts by measuring impacts of *design processes* on racial health equity (e.g., assessments of how much generated design ideas target upstream health determinants would provide early insight into the potential for those ideas to address health equity).
- (3) Designed systems: it is essential to assess the effectiveness of health AI design efforts by measuring impacts of *the designed systems* on improving racial health equity over time.
- (4) Community engagement: to determine if design work is being carried out effectively, it is vital to examine communities' perspectives on how well they are engaged in participatory AI research over time.

## 6.9 A Guiding Principle: Building Community Trust

The final consideration we present is the importance of building community trust, which is paramount for health equity and inclusivity, and is necessary to carry out each of the participatory AI strategies that we put forth in this paper. Communities must feel that they can trust who is behind the creation of health AI systems [235], and the intentions of these tools. Producing co-ideated AI systems cannot be the final stage of these participatory efforts as laid out in some existing frameworks [24, 155]. Scholars note that ending the work here leaves the community not knowing what happens with a system after it is conceived or prototyped [230, 236], having the inverse effect of building trust. Health AI presents a new level of potential skepticism for marginalized communities whose trust in the United States healthcare system has been fractured [17], and who have been harmed by AI and algorithms [127]. *Building* trust thus becomes critical to address well-founded hesitations surrounding health AI systems and to mitigate myths and

misconceptions about AI. Engaging community members in the longitudinal creation and evaluation of health AI may help build trust by establishing relationships with the people behind its development and use. In addition to this engagement, we consider that trust may be built by both the transparency of information and who has a hand in creating that information, and acknowledging the skepticism and traumas that are associated with marginalized populations' interactions with health systems and AI.

## 7 Concluding Thoughts: A Call to Action

Health AI systems are being created and used so rapidly that research on how to effectively engage the public in designing these systems has not caught up [100, 239]. Addressing this challenge and the need to create health AI development processes that are higher quality, more inclusive, and that advance health equity [100, 143, 152, 239], and building upon emerging equitable health AI design research [6], we used our critical review to surface key gaps in prior participatory AI research that hinder progress towards racial health equity, and contribute a set of actionable strategies for closing those gaps.

Given how pervasively AI is already being incorporated into health contexts [4, 39, 65, 93, 184], health AI projects *must* have an equity focus to ensure that they do not create intervention-generated inequities by yielding "innovations" that are less accessible to and effective within racially marginalized groups as compared to other racial groups, as we have seen time and again with health interventions [222]. Given these concerns, our recommendations focus on mitigating racial inequities. However, we stress that intersectional analyses are essential when addressing health inequities, given how oppression and discrimination arising from multiple identities compound to create inequities [129]. As such, our work can help guide health AI research that seeks to mitigate health inequities that exist within groups marginalized due to additional identities such as gender, sexual orientation, geographic location, and disability. While not U.S.-specific given the diversity of work represented in our corpus of articles, this article does have an emphasis on racial health equity issues that arise within a U.S. context. Given the cultural situatedness of issues around race, ethnicity, and racism as they relate to wellbeing, we encourage future work to further examine and build upon the strategies in this paper in diverse national and cultural contexts. We urge those involved in designing, implementing, and evaluating health AI systems to stand for nothing less than creating tools that advance health equity by deliberately addressing racial injustice and additional intersecting forms of marginalization.

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## A Critical Review Approach: Further Detail

Given our interest in understanding participatory approaches to health AI design, we focused our article search on the ACM Digital Library - a premier and extensive database of research, including research focused on AI design and innovation, and human-centered, participatory research. As described in Sections 3.1 and 3.2, we conducted boolean searches of the ACM Digital Library using the following two strings:

String 1: "[[Abstract: ""participatory design"" OR [Abstract: ""co-design"" OR [Abstract: ""community-engaged design"" OR [Abstract: ""co design"" OR [Abstract: ""participatory"" OR [Abstract: ""design""]] AND [[Abstract: health] OR [Abstract: wellness] OR [Abstract: wellbeing] OR [Abstract: disease] OR [Abstract: cancer] OR [Abstract: ""chronic disease"" OR [Abstract: asthma] OR [Abstract: hypertension] OR [Abstract: ""high blood pressure"" OR [Abstract: diabetes] OR [Abstract: diabetic] OR [Abstract: nutrition] OR [Abstract: physical activity] OR [Abstract: ""mental health"" OR [Abstract: stress]] AND [[Abstract: ""artificial intelligence"" OR [Abstract: ""machine learning"" OR [Abstract: ""chatbot"" OR [Abstract: ""ai"" OR [Abstract: llm] OR [Abstract: ""large language model"" OR [Abstract: nlp] OR [Abstract: ""natural language processing"" OR [Abstract: ""deep learning""]] AND [[Abstract: equity] OR [Abstract: disparities] OR [Abstract: inequalit\*] OR [Abstract: disparity] OR [Abstract: marginalized] OR [Abstract: vulnerable] OR [Abstract: underserved] OR [Abstract: minorit\*] OR [Abstract: underrepresented] OR [Abstract: justice] OR [Abstract: black] OR [Abstract: ""african american"" OR [Abstract: hispanic] OR [Abstract: latin\*] OR [Abstract: native] OR [Abstract: indigenous] OR [Abstract: ""pacific islander"" OR [Abstract: hawaii\*]]"

String 2: "[[Abstract: ""participatory design"" OR [Abstract: ""co-design"" OR [Abstract: ""community-engaged design"" OR [Abstract: ""co design"" OR [Abstract: ""participatory ai"" OR [Abstract: ""design""]] AND [Abstract: well-being] AND [[Abstract: ""artificial intelligence"" OR [Abstract: ""machine learning"" OR [Abstract: ""chatbot"" OR [Abstract: ""ai"" OR [Abstract: llm] OR [Abstract: ""large language model"" OR [Abstract: nlp] OR [Abstract: ""natural language processing"" OR [Abstract: ""deep learning""]] AND [[Abstract: equity] OR [Abstract: disparities] OR [Abstract: inequalit\*] OR [Abstract: disparity] OR [Abstract: marginalized] OR [Abstract: vulnerable] OR [Abstract: underserved] OR [Abstract: minorit\*] OR [Abstract: underrepresented] OR [Abstract: justice] OR [Abstract: black] OR [Abstract: ""african american"" OR [Abstract: hispanic] OR [Abstract: latin\*] OR [Abstract: native] OR [Abstract: indigenous] OR [Abstract: ""pacific islander"" OR [Abstract: hawaii\*]] AND [[Abstract: ""participatory design"" OR [Abstract: ""co-design"" OR [Abstract: ""community-engaged design"" OR [Abstract: ""co design"" OR [Abstract: ""participatory"" OR [Abstract: ""design""]]"

Our search resulted in 167 articles being returned (See Supplementary Materials for the full list). After screening the articles for adherence to our inclusion and exclusion criteria (see Section 3.2), we identified 25 articles for inclusion in our corpus (Table 2). These articles report on work that spans several geographic contexts, including North America, the United Kingdom, Latin America, and Africa. Most of the articles that focused on health equity and conveyed their country of focus were situated in United States (U.S.),

and much of the past work articulating racial inequities in health AI has had a focus on the U.S. As such, while our analysis is not explicitly U.S.-centered, it does have an emphasis on racial inequities in this context.

## B Examples of Low-, Mid-, and High-level Design Ideation

Throughout this paper, we discuss the importance of engaging participants in low-, mid-, and high-level design ideation. Here we provide additional examples of how such design work can help advance racial health equity. For example, at a low-level, participants could learn how racial and other biases have crept into datasets and model development [72, 73, 153, 161, 169, 206], how these biases operate at a structural level to preclude access to social determinants of health, steps that technologists have taken to mitigate this bias, and their own views on how such bias should be best mitigated. For example, research can help participants think through the *representational harms*, that is, harms that occur in health AI technologies that reinforce offensive stereotypes and justify oppression, and *allocative harms* that create inequities in resource distributions (e.g., medical algorithms that unfairly preclude Black patients from accessing needed healthcare [153]) [16, 181].

There is also a need for participants' considerations of the social and structural determinants of health during mid-level design ideation of AI systems. In the context of racial equity, researchers and designers can scaffold participants' considerations of how they would want AI driven systems to address social and structural health barriers and facilitators—and cases in which they perceive AI would do more harm than good. For example, research has emphasized how as people age, they move in and out of varied systems (e.g., the educational system and the labor market), that each system presents different ways in which people can experience racial discrimination, and how an individual's experiences of discrimination also impacts others in their social network [71]. Informed by this research, participatory AI efforts could scaffold community members' reflection on how their own and loved ones' experiences with racism have manifested and impacted them at different points in their lives, the opportunities and limits of AI systems for addressing such issues, and how these tools would need to work in conjunction with non-technical interventions to support wellbeing.

Lastly, with respect to high-level design ideation, there are opportunities to support communities in reflecting on social and structural health determinants in the context of overarching objectives and priorities for AI research and innovation, including topics such as articulating grand challenges for the field, maintaining data integrity and quality, supporting equitable data governance, and establishing just forms of AI regulation. Community members can contribute unique and invaluable perspectives as they bring their life experiences to bear on these topics of great societal importance. While academics, healthcare professionals, legislators, and industry professionals have typically been at the forefront of visioning the future of AI [45, 92, 104, 164, 204], there is a need for continued participatory design work that also brings marginalized community members together to articulate their visions for a safe, fair, and just future that involves the responsible use of AI to address the root causes of health inequities [115].

**Table 2: Critical Review Corpus.** This table lists the 14 papers that fully met our inclusion criteria and the 11 papers that partially met our criteria and were included to provide further context for our analysis (the “Met Inclusion Criteria?” column indicates why they were included—because they had a focus on health, equity, design, or a combination thereof).

Title	Authors	Venue	Met Inclusion Criteria?
NLP for Maternal Healthcare: Perspectives and Guiding Principles in the Age of LLMs	Antoniak et al.	FACCT 2024	Yes
Challenge Accepted? A Critique of the 2021 National Institute of Justice Recidivism Forecasting Challenge	Jegade et al.	EAAMO 2023	Yes
Ethical Tensions in Applications of AI for Addressing Human Trafficking: A Human Rights Perspective	Deeb-Swihart et al.	CSCW 2022	Yes
Towards Intersectional Feminist and Participatory ML: A Case Study in Supporting Femicide Counterdata Collection	Suresh et al.	FACCT 2022	Yes
Unpicking Epistemic Injustices in Digital Health: On the Implications of Designing Data-Driven Technologies for the Management of Long-Term Conditions	Bennett et al.	AIES 2023	Yes
Probing a Community-Based Conversational Storytelling Agent to Document Digital Stories of Housing Insecurity	Halperin et al.	CHI 2023	Yes
Invigorating Ubuntu Ethics in AI for healthcare: Enabling equitable care	Amugongo et al.	FACCT 2023	Yes
Intersectional AI: A Study of How Information Science Students Think about Ethics and Their Impact	McDonald et al.	CSCW 2020	Yes
Implementation and Evaluation of a Virtual Hackathon in an Urban HSI Community College during COVID-19	Azhar et al.	Journal of Computing Sciences in Colleges 2023	Yes
Designing Chatbots with Black Americans with Chronic Conditions: Overcoming Challenges against COVID-19	Kim et al.	CHI 2022	Yes
Trust, Comfort and Relatability: Understanding Black Older Adults’ Perceptions of Chatbot Design for Health Information Seeking	Harrington et al.	CHI 2023	Yes
Narratives and Counternarratives on Data Sharing in Africa	Abebe et al.	FACCT 2021	Yes
U.S. Job-Seekers’ Organizational Justice Perceptions of Emotion AI-Enabled Interviews	Pyle et al.	CSCW 2024	Yes
Co-Designing for Transparency: Lessons from Building a Document Organization Tool in the Criminal Justice Domain	Nigatu et al.	FACCT 2023	Yes
Integrating Equity, Diversity, and Inclusion throughout the lifecycle of Artificial Intelligence in health	Nyariri et al.	AH 2022	Partial: Equity+Health
“I Would Like to Design”: Black Girls Analyzing and Ideating Fair and Accountable AI	Solyst et al.	CHI 2023	Partial: Design+Equity
Revolutionizing Methods and Methodologies: Advancing Indigenous-Centered Research Methodologies in User Experience Research (UXR), Technical and Professional Communication Practice	Al-Hassan et al.	SIGDOC 2023	Partial: Design+Equity
Power to the People? Opportunities and Challenges for Participatory AI	Birhane et al.	EAAMO 2022	Partial: Equity
Envisioning Equitable Speech Technologies for Black Older Adults	Brewer et al.	FACCT 2023	Partial: Equity
AI Art for Self-Interest or Common Good? Uncovering Value Tensions in Artists’ Imaginaries of AI Technologies	Jääskeläinen et al.	DIS 2024	Partial: Equity
Consejero automatico: chatbots for supporting Latino parents’ educational engagement	Wong-Villacres et al.	ICTD 2019	Partial: Equity
Envisioning Communities: A Participatory Approach Towards AI for Social Good	Bondi et al.	AIES 2021	Partial: Equity
The Six Conundrums of Building and Deploying Language Technologies for Social Good	Diddee et al.	COMPASS 2022	Partial: Equity
The Situate AI Guidebook: Co-Designing a Toolkit to Support Multi-Stakeholder, Early-stage Deliberations Around Public Sector AI Proposals	Kawakami et al.	CHI 2024	Partial: Design
FATE in AI: Towards Algorithmic Inclusivity and Accessibility	Inuwa-Dutse et al.	EAAMO 2023	Partial: Design