Perspective

Applying anti-racist approaches to informatics: a new lens on traditional frames

Jodyn Platt [1,*], **Paige Nong** [2], **Beza Merid**[3], **Minakshi Raj**[4], **Elizabeth Cope**[5], **Sharon Kardia**[6], **and Melissa Creary**[2]

[1]Department of Learning Health Sciences, University of Michigan Medical School, 300 North Ingalls, Suite 1161, Ann Arbor, Michigan, USA
[2]Department of Health Management and Policy, University of Michigan School of Public Health, Ann Arbor, Michigan, USA
[3]School for the Future of Innovation in Society, Arizona State University, Tempe, Arizona, USA
[4]Department of Kinesiology and Community Health, College of Applied Health Sciences, University of Illinois at Urbana Champaign, Champaign, Illinois, USA
[5]AcademyHealth, Washington, District of Columbia, USA
[6]Department of Epidemiology, University of Michigan School of Public Health, Ann Arbor, Michigan, USA

*Corresponding Author: Jodyn Platt, PhD, MPH, Department of Learning Health Sciences, University of Michigan Medical School, 300 North Ingalls, Suite 1161, Ann Arbor, MI 48109, USA; jeplatt@umich.edu

ABSTRACT

Health organizations and systems rely on increasingly sophisticated informatics infrastructure. Without anti-racist expertise, the field risks reifying and entrenching racism in information systems. We consider ways the informatics field can recognize institutional, systemic, and structural racism and propose the use of the Public Health Critical Race Praxis (PHCRP) to mitigate and dismantle racism in digital forms. We enumerate guiding questions for stakeholders along with a PHCRP-Informatics framework. By focusing on (1) critical self-reflection, (2) following the expertise of well-established scholars of racism, (3) centering the voices of affected individuals and communities, and (4) critically evaluating practice resulting from informatics systems, stakeholders can work to minimize the impacts of racism. Informatics, informed and guided by this proposed framework, will help realize the vision of health systems that are more fair, just, and equitable.

Key words: racism, health equity, medical informatics, learning health system

INTRODUCTION

The field of health informatics is providing critical leadership in the expansion of clinical use of Big Data and the analytic models or tools derived from it (artificial intelligence/machine learning [AI/ML], algorithms, predictive models, decision support, etc.). These innovations are accompanied by large-scale investment in precision health, learning health systems (LHS), and data-driven medicine. They raise hopes for a future of health that improves care delivery for individuals and populations. However, they also raise the specter of digitizing and replicating, at large scale, the inequity and racism embedded in extant systems.[1]

Racism in health care and informatics

Informatics, as an interdisciplinary systems science, is practiced at all levels from the individual to systems and populations. Racism operates in society—and in health care—across these levels, from the individual to the systemic.[2] We focus here on structural, institutional, and systemic racism, which operate independently of any individual or personal racism, prejudice, or attitude (see Figure 1).[2] Each form of racism is chronic and embedded in contemporary systems,[3] including in the hierarchy of data, information, knowledge, and wisdom (DIKW) familiar to informaticists.[4,5] The types of racism

defined above are relevant to each component of the hierarchy, not only because they shape the data underlying informatics tools,[6,7] but because they also shape the healthcare system and society more broadly. Examples—beyond algorithmic bias and representation—that can be observed within the DIKW framework, and foundational to health data, care delivery, and quality, are provided in Table 1.

Frameworks for exposing and addressing racism in informatics: the case for the Public Health Critical Race Praxis

In response to the issues described in Table 1, alternative approaches to understanding how racism can be exposed and addressed have been proposed and conceptualized. Parsons et al,[24] for example, describe an equity-based approach to implementing LHSs that use equity as the foundational and guiding principle to research and practice. Similarly, Veinot et al[25] offer a framework for reviewing and engaging in informatics research by applying an equity lens and Ferryman[19] describes a more equitable process for regulating health informatics tools. There are also new methods and frameworks being used that center the experiences of marginalized populations by examining community-level patterns[26] and by unmasking biases in stratification.[9,27,28]

Systemic racism (3)

Structural racism (1)

Institutional racism (2)
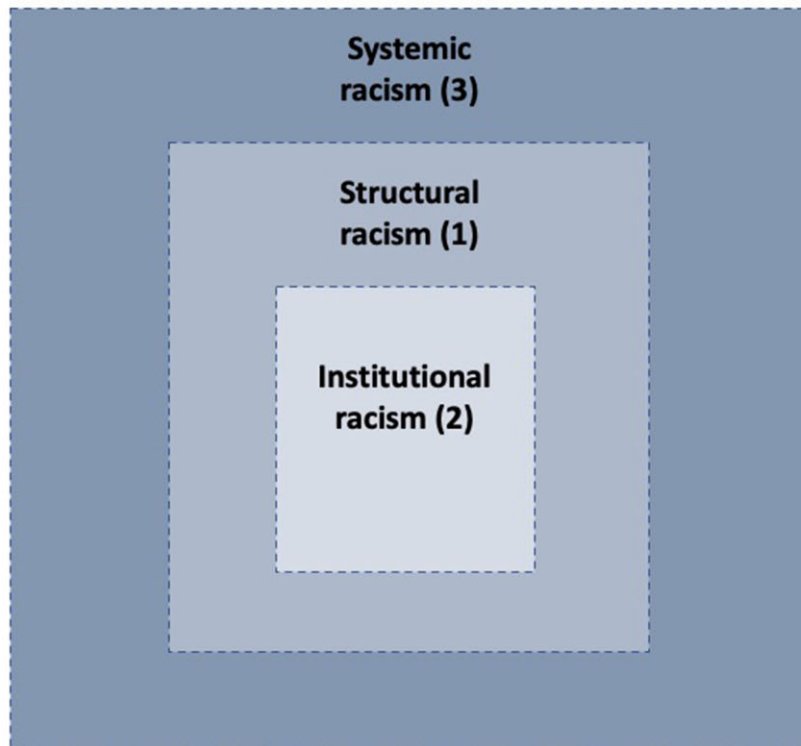
1. Structural racism emerges from the historical and deeply entrenched connectivity of institutions that reinforces discrimination across one another; for example, the ways in which housing, education, employment, income, and health care are unequal and reinforce discriminatory beliefs and the allocation of resources, resulting in the perpetuation of racism and discrimination across all of these structures.[a]

2. Institutional racism is a form of structural racism, identified in the norms, customs, policies, and practices of organizations and social systems.[b] For example, institutional racism has a direct impact on data quality for informatics because of disparities in access to care.[c] The lack of care available to many reflects exclusionary attributes of an organization that can operate independently from the intentions of individual people working in that organization.

3. Systemic racism encompasses institutional and structural racism but also explicitly considers hierarchy and history, taking into consideration the effects and impact of centuries-long histories of slavery, segregation, settler colonialism, and White privilege.[d]

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Figure 1. Types of racism.

Table 1. Some examples of racism in healthcare and its connection to the Data-Information-Knowledge-Wisdom Hierarchy: implications for quality

	Institutional racism	Structural racism	Systemic racism
Data Symbols[4]	Data collection fidelity in the clinic is often dependent on racial (mis)-match between patient and provider[8] Quality measures in care provision are often not stratified by race/ethnicity[9] Lack of access to healthcare institutions leads to lack of representation in data[10]	Invisible racial/ethnic categorization of patients (eg, Middle Eastern/North African are not recognized on forms and misclassified or classified as "other")[11] Major health datasets reflect inadequate treatment of Black and Hispanic patients[12]	Higher quality data systems for predominantly white healthcare settings[13] Lack of unified electronic health record system creates disparities for data collection in low resource (predominantly minority serving) clinics[10]
Information = Data + meaning[4]	White patients have greater access to certain medications or procedures, with higher expenditures on their care compared with their Black counterparts[7] Racial/ethnic disparities in healthcare outcomes are ascribed to patient characteristics rather than healthcare institutional characteristics	"Risk" is inappropriately assigned to Black and Latinx patients, limiting access to care[14]	Historic and contemporary racism in society (e.g., legally and *de facto* racially segregated hospitals) shape healthcare and outcomes[15]
Knowledge Application of data and information to answer "how" questions[4]	EHR data reflects interpersonal racism[1] Interpretation of information and knowledge generation occurs in a field that lacks workforce diversity. Chronic underrepresentation of women and minorities in science, technology, engineering, and math (STEM) limits opportunities for entry into informatics workforce[16]	Through individualized measures and interventions, informatics approaches can fail to account for the key structural issue of digital redlining[17] Systems of review do not exist or are not examining impact on equity[18]	Informatics tools, and informatics-driven care perpetuate and entrench patterns of inequitable care by using data without accounting for systemic racism[7] Federal funding favors white principal investigators over non-white PIs[19]
Wisdom Building on knowledge to answer "why" questions[4]	The cause of racialized quality gaps is often missing or misattributed to other circumstances (e.g., patient health behaviors)[20]	Quality care is more accessible to white patients because of residential segregation and proximity to well-resourced health systems (eg, Yale's hospital and health systems' workforce does not reflect New Haven community or populations)[21]	Efforts to build racial health equity or equitably deploy informatics tools continue to be constrained by histories and contemporary realities of racism[22] Healthcare systems focus on equality, not equity[23]

Here, we propose the use of an explicitly anti-racist framework and approach, that is, the anti-racist Public Health Critical Race Praxis (PHCRP) for informatics research, education, and practice to directly engage with upstream structural, institutional, and systemic racism. Anti-racist approaches have the goal of confronting and dismantling racism using action-oriented and structural analyses that enable justice, recognize historical roots of inequity, and empower people who have been excluded.[29,30] The PHCRP was developed to help people in interdisciplinary and multi-professional fields become more self-reflective about their work, its relationship to racism, and its impact.[31]

We chose the PCHRP-based approach for informatics because of its interdisciplinary focus, strong theoretical foundation, and focus on application in real-world settings that can guide informatics professionals and health systems toward specific actions that can produce higher-quality, more equitable care. A PHCRP-based approach could be applied for research and interventions intended to improve health equity such as the development of a more equitable predictive model for emergency room discharge and its implementation into CDS, a retrospective study comparing telehealth outcomes with outcomes of in-person care, surveillance of opioid-related deaths, or the development of an mHealth intervention to assist women in self-monitoring for postpartum complications. Using the PHCRP would prompt people involved with these activities to review prior assumptions and personal biases, appropriate measurement and evaluation, and reveal expertise that maybe missing from a study or intervention team.

The PHCRP has 3 core functions. First, it establishes the norms and assumptions of awareness and recognition of racial position, embedded racism, and the implicit hierarchy of "colorblindness." Second, the praxis articulates the fundamental connection between societal problems on the one hand and social constructions of race, macro-level factors, and racial and other forms of inequity on the other. Third, the PCHRP provides a starting point for dismantling racism through the evaluation of knowledge using anti-racist methods, developing comprehensive understandings of bias, reflexivity, and recognition and respect for multiple social identities and "centering at the margins" or prioritizing the perspectives of people who have historically been excluded from power structures.[31,32]

The praxis includes 4 focal areas that shape activities in research and practice: contemporary race relations, conceptualization/measurement, knowledge production, and action. These focal areas are analogous to concepts and approaches

Table 2. The PHCRP-Informatics framework: aligning PHCRP research focus areas and informatics practice

PHCRP research focus areas	Contemporary race relations Salience of structural racism during study time/context	Conceptualization/ measurement Operationalization of racism-related variables, including intersectionality	Knowledge production How racialization may shape LHS work or how the LHS may reinforce structural racism	Action How findings help to dismantle power differentials between community and researchers, benefit community, and counteract racism
Application to DIKW hierarchy and examples of Informatics analogs	**DIKW** Sociotechnical systems Ux design Stakeholder engagement	**DI** Standards development Research design Measurement	**K** Advanced analytics CDS tools AI tools Knowledge representation	**W** Implementation and outcomes
Anti-racist approach in informatics	Focus on relationships: Who are the stakeholders and how do social and technical systems interact? How are different forms of racism operant? Do our research and practice teams adequately recognize and understand racism? Do they include expertise in anti-racism? How is community represented? How are stakeholders represented and empowered? Have we examined our positionalities and priorities through the lens of anti-racism? How is racism operating in micro to macro operations (not *if*).[33]	What information is collected? What information is missing? Is it sufficient for all groups? Where are the gaps? Does our data include appropriate measures of structural or macro-level factors? Do we account for intersectionality and/or interactions of different identities and experiences? Are the data constructs valid for all populations? How have we accounted for and/or considered racism and bias? Are we conflating race and racism?	Does interpretation/inference reflect the lived experiences of the populations affected by this work? How might this knowledge be interpreted and used? Could this reflect harmful histories of knowledge production? Is interpretation biased? (eg, are we valuing whiteness in our choice of reference groups?)	What is the impact of implementation on equity? How is performance evaluated? Does this account for appropriate social and temporal contexts? Does evaluation center the voices and perspectives of marginalized people?

familiar to informatics researchers and professionals who focus on DIKW in sociotechnical systems, research design, standards development, advanced analytics, and implementation. Below, we apply the 4 focal areas of the PHCRP to informatics work using the DIKW hierarchy.

The PHCRP-informatics framework

In the section below, we describe the key PHCRP focus areas and their implications for informatics as they relate to issues in DIKW. In Table 2, we propose exemplary questions for introspection for individuals, groups, and organizations to facilitate framing and practice as a "PHCRP-Informatics Framework."

Focal area 1 contemporary race relations: System design, stakeholder engagement, and user experience (DIKW)

Contemporary theories and practice in academic fields, including health informatics, stem from their historical antecedents in scientific disciplines with long legacies of racist exploitation and exclusion.[34–36] Table 1 lays out how these become salient in the DIKW hierarchy; Table 2 lists a set of questions that would help people anticipate them. Awareness at each of these DIKW levels, combined with understanding of contemporary race relations, can guide informatics work toward equity. Engaging in processes of critical self-reflection in the field of informatics (ie, within the discipline) and at the individual level is a critical first step. Self-awareness also entails recognizing anti-racism as an area of expertise necessary for interdisciplinary work and seeking out forms of

knowledge that have not traditionally been a part of research or clinical enterprises. Reflexive work must include all stakeholders, those in power and those who bring knowledge and lived experiences of marginalized racial and ethnic group into informatics systems.[37] The goal of this work is to implement the principle of *Voice*,[31] making equity a central, and explicit, concern in work such as system building, user experience, and sociotechnical design work.

Focal area 2 data and information: Research design, standards development, measurement (DI)

A PHCRP-informatics framework leads us to consider what information is being collected, what is measured, and how standardization creates criteria for inclusion and exclusion. The notion of *Intersectionality*[31,38,39] highlights the complexity of decisions made about who is counted, what information is collected, and how it is represented. Intersectionality captures a multiplicity of identities and histories, even within single individuals. These may be flattened or lost in the digitization and computational nature of health research when we implicitly or explicitly treat groups (eg, Black people, women, low-income people, etc.) as monolithic. Informatics capabilities should be applied to better understand intersectionality in healthcare. Furthermore, the data we have about experience are insufficient.[40] We cannot account for and improve what we do not measure, and this includes racism and White privilege or advantage. Data collection efforts should aim to capture racism embedded in health systems and evaluate data for construct

validity with an examination of limitations and/or implications of using proxies when direct measurement is not possible.[41,42]

As social determinants of health become a more routine data consideration, collecting information about individual behaviors designed to indicate need for individual-level interventions does not address the social and policy factors that (by definition) shape social determinants of health.[17] Furthermore, data standards and conventions may occlude differences in how people self-report conditions or obscure nuances in racial or ethnic identities, contributing to the creation of biased measures.[43]

Focal area 3 knowledge production: Knowledge representation, AI tools, clinical decision support (K)

Knowledge production ideally recognizes the social construction of medical knowledge,[44] engages critical approaches, and identifies the salience of stakeholder voices. In reviewing research findings, interpretations, and inferences, the PHCRP-Informatics approach demands examination of whether and how the knowledge reflects lived experiences of the populations served, and whether they have accounted for or considered the implicit biases of their work.[26] This includes, for example, assessing the impact of reference groups in the interpretation of findings.[27] It can also mean careful articulation of the generalizability of findings when underlying data structures are biased in their inclusion of marginalized groups.

For example, there is some evidence that people withhold information from their clinicians, and thus from their medical records and potential data sources, when they perceive harm may come to them from sharing information or they do not trust clinicians with the information.[33,45,46] Accounting for this dynamic and contextualizing its relationship to racism are an important step in moving data and information toward higher quality knowledge and wisdom in health informatics.

Focal area 4 action: Implementation and outcomes (W)

In the Action area, the PHCRP-Informatics framework provides a set of questions for examining the impact of informatics tools, programs, and processes. Addressing these questions in planning can stave off some of the "unforeseen" (but predictable) consequences of interventions, and would enhance the Wisdom domain of the DIKW hierarchy.[47] Applying the PHCPR-Informatics framework will require impact assessments as well as empirical evaluation and development of appropriate measures. Including voices and perspectives of marginalized people is integral to each phase of the praxis, including real-world implementation as well as governance, proposed institutional policy changes, and evaluating practice. These practices are consistent with guiding principles of community-based participatory research, which include community-driven agenda setting, community involvement in leadership, and collaborative dissemination of findings.[48]

DISCUSSION: SUMMARY AND FUTURE WORK

The PHCR praxis was developed in the context of public health research. Others have used this and similar methods to apply an anti-racist lens to fields such as implementation science, health data science, and precision health.[49–51] The PHCRP-Informatics framework laid out above provides a roadmap for navigating the DIKW hierarchy that engages with racism and explicitly works to protect individuals and communities harmed by it.

Starting as a practice of self-reflection, individuals, teams, organizations, and systems can apply the framework to existing informatics work, from education to research to practice. For example, Coley and Huff[34] developed a workshop for engineering professionals to confront white supremacist culture in STEM. The PHCRP-Informatics framework could be used to expand this work and to further develop competencies and training. Curricula to train leaders and researchers to seek out the literature on racism, disparities, and justice should be a priority so that teams can identify relevant questions and variables that they might not have otherwise considered. Evaluation that demonstrates the value of PHCRP-informatics work to leadership and participants should equally be pursued. Including scholarly and community expertise in anti-racism in team-based research, education, and practice will ensure meaningful engagement with the PHCRP-Informatics framework.

The PHCRP-Informatics framework also elucidates new areas of research and practice and the need for: (1) research questions that more accurately address the knowledge gaps impacting system operations and populations, including naming and monitoring/measuring how racism operates in information systems; (2) thorough and comprehensive standards around data analysis that account for appropriate measurement and confounding variables; (3) production of knowledge that is more reliable, responsive, and robust to the needs of marginalized communities; and (4) practice recommendations that comprehensively address their implications for people, systems, and systemic racism.

Using the PHCRP should be seen as a point of departure for systemic change that allows for a more robust engagement with DIKW as a central pillar of informatics theory. At a conceptual level, the PHCRP raises questions that can reveal underlying inequity and racism in a system—from data to wisdom. As a practical matter, use of the PHCRP in the development of an improved predictive model for emergency room discharge, for example, should prompt developers and end users to consider appropriate measurement, the variables used in the model, and the assumptions behind any proxy variables that are used. In the implementation of the model in CDS, use of the PHCRP would raise additional, explicit, considerations about access, quality, and patient interactions with clinicians and health care systems.

It is important to recognize that implementing this proposed PHCRP-informatics framework is far more challenging in practice than it is in theory.[22] It can be perceived as abstract, particularly when mitigating racism and creating equitable systems seems infeasible. Even when people agree to the principles, learning and implementing change for an anti-racist future is not a single destination but a continuous pursuit and will demand the renegotiation of power and governance. The praxis is limited in that it does not solve the problems of fragmentation and competing interests, but it does highlight critical first steps that incorporate all stakeholders. This work of understanding the role racism plays in health informatics itself fulfills a key requirement of moving from data to wisdom.

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All authors made substantial contributions to the conception and design of the work. JP and PN drafted the work; all authors provided critical revisions, final approval, and agree to be accountable to all aspects of the work.

CONFLICT OF INTEREST STATEMENT

None of the authors have competing interests to declare.

DATA AVAILABILITY

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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