
Editorial

Health informatics and health equity: improving our reach and impact

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ABSTRACT

Health informatics studies the use of information technology to improve human health. As informaticists, we seek to reduce the gaps between current healthcare practices and our societal goals for better health and healthcare quality, safety, or cost. It is time to recognize health equity as one of these societal goals—a point underscored by this *Journal of the American Medical Informatics Association* Special Focus Issue, “Health Informatics and Health Equity: Improving our Reach and Impact.” This Special Issue highlights health informatics research that focuses on marginalized and underserved groups, health disparities, and health equity. In particular, this Special Issue intentionally showcases high-quality research and professional experiences that encompass a broad range of subdisciplines, methods, marginalized populations, and approaches to disparities. Building on this variety of submissions and other recent developments, we highlight contents of the Special Issue and offer an assessment of the state of research at the intersection of health informatics and health equity.

WHY HEALTH EQUITY AND HEALTH INFORMATICS? WHY NOW?

This Special Issue responds to an urgent need for advances in knowledge at the intersection of health informatics and health disparities. We live in an era of widening inequality worldwide, especially in relation to income and wealth¹—a fact that draws the negative impacts of inequality, such as differential health outcomes, into sharp relief. Moreover, in the United States, despite notable, coordinated governmental investments over several decades, troubling and substantial health disparities persist. The evidence is indisputable that differences in a range of health outcomes are linked to socially stratifying factors such as race and ethnicity, socioeconomic status (SES), disability, rural residence, and LGBTQ identities (“sexual and gender minorities”). Such disparities have been documented in infant mortality and preterm birth, childhood obesity, mental health challenges, injuries, chronic conditions such as cardiovascular dis-

ease and cancer, and life expectancy.^{2–7} Moreover, Galea et al⁸ showed that 874 000 deaths were attributable to social causes such as low education, racial segregation, low social support, poverty, and income inequality in the year 2000 in the United States.

In addition, recent changes in the United States have intensified the need for work at the intersection of health equity and health informatics. The Affordable Care Act of 2010 improved access to health care among previously uninsured Americans. Shifts in healthcare reimbursement to value-based care have forced healthcare organizations to respond to the impacts of the social determinants of health on patient health outcomes. The Health Information Technology for Economic Clinical Health Act’s stimulation of widespread adoption of electronic health records (EHRs) has led to increasing reliance on EHRs for care delivery. And although not all Americans use the Internet or smartphones, increases in adoption rates among all ages and socioeconomic groups offer new opportunities for communication, support, and intervention in the service of health.

On the other hand, with this computerization of society, we are also more likely to encounter unintended and negative consequences of computing. Recent ethical debates have focused on the responsibilities of computer science professionals and technology companies for the impacts of the technologies that they create, such as Hecht et al.⁹ and Gotterbarn et al.¹⁰ In health informatics, parallel concerns have arisen about the potential for intervention-generated inequality resulting from informatics interventions,¹¹ and the potential for bias involved in the application of machine learning and other data science methods to health care.¹²

This need for health equity-focused informatics research is clearly appreciated by our broader research community. Indeed, the Guest Editorial Committee was heartened to receive 68 submissions for the Special Issue, resulting in the acceptance of 23 articles—enough for the present double issue. Furthermore, we are pleased at the number of first-time *Journal of the American Medical Informatics Association (JAMIA)* authors in this issue, with 103 of 143 unique authors being first-time *JAMIA* authors. In the majority of articles, at least 1 author had published in *JAMIA* before; however, all authors of 7 articles had no previous *JAMIA* publications. Notably, this included authors who primarily publish in other fields such as computer science and public health. These patterns suggest that authors experienced with *JAMIA* publication might have established new teams to address the issue of health equity and that some new authors were drawn to *JAMIA* because of the health equity focus, thus enriching the perspectives offered on health informatics-based health equity solutions.

This *JAMIA* Special Issue joins broader conversations that are ongoing in related fields. For instance, the Computing Community Consortium and Society for Behavioral Medicine hosted a national workshop in April 2018 entitled “Sociotechnical Interventions for Health Disparity Reduction,” which resulted in the recent publication of a national research agenda.¹³ In the United States, the National Institute of Minority Health and Health Disparities (NIMHD) has also catalyzed work in this area through multiple initiatives. In June 2019, the health services research journal, *Medical Care*, published an NIMHD-funded supplement on “Addressing Health Disparities through the Utilization of Health Information Technology” as a follow up to an NIMHD-funded workshop. Also funded by NIMHD, a January 2019 supplement of the *American Journal of Public Health* on health disparities research included articles focused on technology.^{14,15} A recent funding opportunity at NIMHD also focused on “Technologies for Improving Minority Health and Eliminating Health Disparities.”¹⁶ Several 2019 workshops from other NIH Institutes concerning health disparities have also incorporated sessions on health information technology.¹⁷

With such work occurring in parallel fields, what are the unique contributions of health informatics? In our view, health informatics is unique in its simultaneous focus on—or “cross-training”¹⁸ in—health domain areas, information sciences and technology, and the social or behavioral sciences.¹⁹ As reflected in this Special Issue, this results in unique topical emphases such as technology implementation and uptake, support for clinical research, basic research on user requirements, health information needs and information seeking, data quality, interventions embedded in clinical information systems, and technology infrastructures such as standards.

THE STATE OF RESEARCH IN HEALTH INFORMATICS AND HEALTH EQUITY: WHAT THIS SPECIAL ISSUE TELLS US

We now review the articles included in this Special Issue, discussing only those articles that were ultimately included—although included

articles are broadly representative of the types received for the Special Issue. Health disparity researchers differentiate between 3 “levels” of research necessary to make progress on disparity reduction: (1) detecting disparities, (2) understanding why disparities exist, and (3) reducing disparities, which involves design, implementation and evaluation of interventions.²⁰ Table 1 shows that several included articles demonstrate the potential for informatics research to detect disparities and groups that experience disparities. One approach in the included articles was to test novel methods for identifying the existence of populations that experience disparities; these articles used text and image data, respectively.^{21,22} Studies of data quality compared data in official sources with one another, or to a “ground truth” source, so as to help us understand the limitations of existing data sources for investigating disparities.^{23–25} One study, an Editor’s Choice in this Special Issue, evaluated disparities the classification of opioid overdose deaths in official U.S. government sources,²³ whereas 2 focused on EHR data quality. Furthermore, 2 studies used EHR and digital trace data to document disparities in access to, and uptake of, patient-facing technologies.^{26,27} Two studies also used digital trace data from social media to characterize the experiences and needs of marginalized populations as they faced social or health-related transitions.^{28,29} Another article described a research infrastructure facilitating creation of an online cohort of research participants—an approach that will ultimately facilitate better characterization of health disparities among sexual and gender minorities.³⁰

Considerably fewer studies in this Special Issue aimed to help us understand why disparities exist. Such studies necessitate studying potential mediators or moderators of interventions—that is, pathways by which interventions may reduce disparities. Accordingly, such studies typically utilize, develop, or test theories or models. In the Special Issue, only 2 studies attempted to explain disparities using theory. One characterized the use of psychosocial information in outpatient diabetes care, demonstrating that its use may be related to adaptations to care plans for patients experiencing psychosocial challenges.³¹ The article, an Editor’s Choice, contributes 2 models depicting when and how clinicians use psychosocial information in the care of marginalized diabetes patients.³² Another article uses the e-Health Equity Framework to analyze existing research on patient portals.³³ The article shows that research on patient portals has primarily focused on removal of individual-level patient barriers to use at the expense of taking socioeconomic and political determinants of inequitable health outcomes into account.³³ Hence, this work ultimately points to some reasons why portal projects may ultimately fail to enhance health equity.

As for articles focused on reducing disparities, articles included research and frameworks to inform design of new interventions to meet stakeholder needs,^{34–37} evaluations of interventions that have been deployed,^{38–41} and a systematic review of prior interventions.⁴² One article, a perspective piece, also argued for expanded collection of social determinants of health data in mental health care³² and a case report outlined the challenges of participation in a pragmatic trial within small, immigrant-serving healthcare practices.⁴³ Interventions in development included personal health records for new settings and audiences.^{34,36} Another article highlighted rural public health practitioners’ information and training needs in preparation for an intervention.³⁵ Clinical informatics interventions that were evaluated aimed to promote use of preventative services, and improve rural residents’ healthcare access.³⁹ An additional 2 interventions sought to recruit diverse populations to participate in research by embedding information about research participation opportunities into existing clinical information systems.^{40,41}

Table 1. Categorization of articles by level of health disparity research, informatics domain, marginalized population, extended WHO model of health disparities level of intervention and intervention target

First Author	Health Disparity Research Level	Informatics Domain	Marginalized Population per PROGRESS-Plus Factor	Extended WHO Model Level of Intervention	Extended WHO Model Intervention Target
Antonio	Understanding	Consumer health informatics	Place of residence, race/ethnicity/culture/language, education and/or socioeconomic status, disability or chronic conditions	N/A	N/A
Bekemeier	Reducing	Public health informatics	Place of residence	Meso: living and working conditions	Reducing exposures
Boslett	Detecting	Public health informatics	Place of residence, race/ethnicity/culture/language, education and/or socioeconomic status, age	N/A	N/A
Bruzelius	Detecting	Public health informatics	Place of residence	N/A	N/A
Chen	Detecting	Clinical informatics	Age, disability or chronic condition	N/A	N/A
Cullen	Reducing	Clinical informatics	Race/ethnicity/culture/language	Meso: health system	Preventing unequal consequences of ill health
Deferio	Reducing	Clinical informatics	Race/ethnicity/culture/language, education and/or socioeconomic status, disability or chronic condition	Meso: health system	Preventing unequal consequences of ill health
Dexheimer	Reducing	Consumer health informatics	Age	Meso: living and working conditions	Decreasing vulnerability
Divney	Reducing	Clinical research informatics	Race/ethnicity/culture/language	Meso: health system	Preventing unequal consequences of ill health
Feldmeth	Reducing	Clinical research informatics	Race/ethnicity/culture/language	Meso: health system	N/A
Fiore	Reducing	Clinical informatics	Age, education and/or socioeconomic status, gender/sex	Meso: health system	Reducing exposures
Grossman	Reducing	Consumer health informatics	Place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education and/or socioeconomic status, social capital, disability or chronic conditions	Meso: health system	Preventing unequal consequences of ill health
Haimson	Detecting	Consumer health informatics	Sexual or gender minorities	N/A	N/A
Javier	Detecting	Consumer health informatics	Race/ethnicity/culture/language	N/A	N/A
Kannan	Reducing	Clinical research informatics	Gender/sex, race/ethnicity/culture/language	Meso: health system	N/A
Khairat	Reducing	Clinical informatics	Place of residence	Meso: health system	Preventing unequal consequences of ill health
Lee	Detecting	Consumer health informatics	Sexual or gender minorities	N/A	N/A
Lunn	Detecting	Clinical research informatics	Sexual or gender minorities	N/A	N/A
Polubriaginof	Detecting	Clinical research informatics	Race/ethnicity/culture/language	N/A	N/A
Senteio	Understanding	Clinical informatics	Place of residence, race/ethnicity/culture/language, education and/or socioeconomic status, disability or chronic conditions	Meso: health system	Preventing unequal consequences of ill health
Sholle	Detecting	Clinical research informatics	Race/ethnicity/culture/language	N/A	N/A
Toscos	Detecting	Consumer health informatics	Age, education and/or socioeconomic status, disability or chronic conditions	N/A	N/A
Were	Reducing	Consumer health informatics	Place of residence, education and/or socioeconomic status	Meso: health system	Preventing unequal consequences of ill health

N/A: Was not an interventional study; WHO: World Health Organization.

Using a more classic categorization, the articles represent 4 foundational domains of health informatics: clinical informatics ($n=6$), clinical research informatics ($n=6$), consumer health informatics ($n=8$), and public health informatics ($n=3$) (Table 1). The clinical informatics articles describe efforts to identify patients with emerging disabilities using EHR data,²² discussions of the potential for social determinants of health data in clinical care,^{31,32} evaluations of interventions to increase use preventative services,³⁸ and access to care for rural populations.³⁹ A perspective article also details planning considerations for clinical information systems in the Indian Health Service.³⁷ Published articles in clinical research informatics highlight data quality concerns related to information about marginalized groups^{24,25} and small healthcare practices that often serve them.⁴³ Three articles also outlined use of technology to recruit marginalized groups to participate in research.^{30,40,41} For the work in consumer health informatics, we note that these articles primarily dealt with patient portals or personal health records,^{26,33,34,36,42} with an additional 2 articles using digital trace data from online communities or social media as research data.^{28,29} One study also addressed access to patient-facing remote monitoring technologies.²⁷ In keeping with the core functions of public health, 2 public health informatics articles focused on disease or population surveillance.^{21,23}

Studies in this Special Issue also focus on a range of marginalized populations. Table 1 classifies included articles based on the PROGRESS-Plus typology.⁴⁴ As shown, the majority of articles addressed populations based on multiple disparities ($n=10$); race, ethnicity, language, or culture only ($n=5$ articles); sexual or gender minorities only ($n=2$); and place of residence only ($n=2$). A smaller proportion focused on analyses 4 PROGRESS-Plus factors: men or women as experiencing disparities, occupation, religion, and social capital. Furthermore, of the accepted articles, only 2 focused on work conducted in the Global South.^{21,36}

Interventional research

Assessment of the interventional research included in this Special Issue (ie, those focused on reducing disparities) reveals that the majority of interventions focused on health outcomes targeted healthcare system practices, and existing patient populations for whom prevention of unequal consequences of ill health are most salient. Table 1 classifies included studies according to a recently published, informatics-oriented extension of the World Health Organization Model of Health Disparities.⁴⁵ The model includes 3 levels of intervention (macro level, meso level, micro level) and 4 intervention targets: (1) influencing social hierarchies, (2) reducing exposure, (3) decreasing vulnerability, and (4) preventing unequal consequences of ill health. Categorization of the articles according to this model shows gaps in the potential types of interventions. Specifically, no interventions targeted the macro level or “influencing social hierarchies.” Further, only 3 studies addressed exposures and vulnerability: 1 focused on public health professionals and 2 extended the reach of clinical care to social and other ancillary services. In addition, 2 interventional studies were conducted in health systems, but did not focus on health disparities per se, but rather on recruiting marginalized groups into clinical studies.^{40,41}

FUTURE DIRECTIONS FOR RESEARCH ON HEALTH EQUITY AND HEALTH INFORMATICS

The articles in this *JAMIA* Special Issue highlight some priority areas for further work at the intersection of health informatics and health

equity. First, to date, health informatics research primarily focuses on detecting and reducing health disparities, but rarely on understanding them. Consequently, there is a lesser focus on theoretical explanations of health disparities in health informatics research than in related fields such as behavioral medicine and public health. This gap is chiefly felt in 2 areas: (1) observational research regarding the role of technology in producing or ameliorating disparities, as identified in Veinot et al¹¹, and (2) designing and evaluating informatics interventions. With regard to observational research, we see a critical need for theory to help explain relationships between technology and health disparities. Empirically, we see potential to build on insights about Internet access as a determinant of health,⁴⁶ the potential for algorithmic biases in health and health care,⁴⁷ and the role of technologies in fostering resilience among marginalized people and communities.^{45,48}

In terms of designing and evaluating informatics interventions, we highlight the limited number of studies of “universal” informatics interventions (ie, intended to be implemented for all) that have considered equity impacts. We also stress that the related evidence, where it exists, is mixed. For instance, in this Special Issue, 2 studies specifically examined specific effects of universal interventions on marginalized populations. A study of referral to smoking quitlines in primary care found that an EHR-based eReferral resulted in a significant increase in referrals when compared with a fax service, and that the gain in referrals was larger among Medicaid patients.³⁸ Another study showed that invitations to participate in clinical research via a patient portal resulted in a larger number of women volunteering for research than is typical, but that specific racial and ethnic groups remained underrepresented among research participants after the intervention.⁴⁰ Similarly, other equity evaluations of universal informatics interventions have yielded mixed results. Clinical reminders that have been otherwise shown to have a positive average treatment effect have, upon closer inspection, variably favored disadvantaged groups,^{49,50} advantaged groups,⁵⁰ and neither group.⁵¹ Furthermore, an evaluation of universally applied audit, feedback, and patient registries as a strategy for practice-level performance improvement in patient blood pressure control showed overall improvement, but that the intervention favored advantage groups in terms of race, ethnicity, and SES.⁵² At the same time, 2 targeted interventions for clinicians serving immigrant patients that used default care processes such as order sets and care pathways resulted in improvement of care process outcomes⁵³ and health outcomes among patients.⁵⁴

This mixture of outcomes are, unfortunately, currently difficult to explain—in part because studies that report equity effects of universal interventions are often descriptive in design, such as Jean-Jacques et al⁵⁰ and Fortuna et al,⁵² rather than reports of moderation or stratified analyses. Consequently, we have little understanding of whether universal or targeted interventions tend to uniformly work better for reducing disparities, or why. Furthermore, little is known about when universal or targeted intervention approaches should be used, and about the feasibility of each in routine care—especially in light of clinicians’ many competing priorities. In essence, many informatics interventions function as “black boxes” in which mechanisms of action and contextual enablers or barriers are unclear. Hence, there is a need for concerted comparative research regarding intervention approaches, their mechanisms of action, and their relative effectiveness in different contexts. Moreover, following articles published in this Special Issue, there is a need to continue to compare interventions throughout the complete “intervention cycle,”¹¹ from access²⁷ to uptake²⁶ to adherence or usage⁴² to effectiveness.

With regard to levels of intervention, the focus of existing research as exemplified in this Special Issue is on the healthcare system and patients. This points to clear opportunities to impact health disparities through a wider range of intervention targets and levels of intervention. As we have argued elsewhere, “upstream” informatics interventions are a promising approach—especially interventions that do not heavily rely on individual effort, behavior and choice among marginalized people.⁴⁵ Following several examples in this Special Issue,^{34,35} such interventions could aim to reduce exposures or decrease vulnerability by targeting upstream decision makers,³⁵ and facilitating information sharing across community services and health care.³⁴ Two observational studies in the Special Issue also illustrate the potential of sexual and gender minorities to develop supportive online social networks,^{28,29} highlighting the potential for more intervention studies for specific marginalized groups via social media. More broadly, there is also potential for interventions to function at the macro level by influencing social hierarchies; however, we acknowledge that this may require large-scale, multisector efforts and policy change.

As described previously, the articles included in this Special Issue addressed a number of marginalized populations. We caution that with a significant reliance on EHR data in health informatics research, there can be a tendency to emphasize disparities that are captured in such data. However, for some health issues or interventions, more difficult-to-measure constructs such as health literacy and SES may equally or more important. In the case of SES, disparities in health have been related to SES for mortality, chronic conditions, and birth outcomes.⁵⁵ Yet, conclusions regarding these relationships may vary depending on whether SES is measured as personal or family income, wealth, education, occupation, or neighborhood SES.⁵⁶ Presenting its own challenges, fine-grained measures of health literacy can be difficult to implement in healthcare, and people with low literacy may be loath to disclose this fact to healthcare providers. Despite these challenges, we encourage informatics researchers to measure such factors strategically based on study aims, while accounting for the multidimensionality of these constructs.

We further contend that health informatics researchers have much to contribute to broader understanding of health disparities and health equity. The articles included in this Special Issue illustrate 2 ways in which informatics methods can assist in this broader understanding: use of health informatics techniques to detect disparities^{21,22} and determining the limitations of existing data.²³ In addition to the types of articles submitted to this Special Issue, we believe that there is tremendous potential for informaticists to leverage large-scale data sources such as cross-institutional repositories to answer critical disparity-relevant questions about disease etiology, prognosis, and treatment effects. In particular, such data may help to facilitate subgroup analyses that would otherwise be infeasible. Additionally, there are opportunities to investigate questions that would be unethical to investigate via randomized controlled trials. For example, there is potential to investigate known differences in the efficacy in prostate-specific antigen screening in African American as compared with White men.⁵⁷ However, to conduct rigorous studies of this nature, it will be necessary for more informaticists to utilize methods to assist in causal inference, such as propensity score matching and quasi-experimental designs in our studies. Relatedly, it will also be important for informaticists to understand, and correct for, biases in available datasets; for instance, sicker patients tend to have more data in their electronic health records and lower-income people are more likely to be uninsured or underinsured,⁵⁸ potentially reducing number of visits to healthcare

providers and thus the amount of data available about them in clinical datasets. Finally, building on a tradition in health informatics,^{59,60} we believe that informatics researchers are uniquely positioned to contribute to understanding equity-relevant unintended consequences of health technologies.

CONCLUSION

We conclude by thanking the reviewers for this Special Issue listed at the back of this issue—particularly our Guest Editorial Committee members who valiantly reviewed a larger number of submissions than expected (see Acknowledgments). As a result of their efforts, and that of other reviewers, this Special Issue of *JAMIA* on health equity has resulted in a series of exciting articles that examine marginalized and underserved groups, health disparities, and health equity. Included articles were from each of the foundational domains of health informatics, focused on a range of marginalized populations, and primarily contributed to detecting and reducing disparities. Articles describing interventions typically focused on the healthcare system and, through a focus on patient populations, reduction of unequal consequences of illness. We highlight several needs and opportunities for future work at the intersection of health informatics and health equity, including a need for more theory-informed research, evaluations of the equity impacts of interventions, and novel upstream informatics interventions. Methodologically, based on evaluation of opportunities in this space, we also emphasize the need for expanded measurement of SES and health literacy, as well as leveraging large data sets to investigate health equity-relevant questions—with subgroup analyses at a scale that has not previously been possible. Although we are excited to present the collection of articles in this Special Issue, much work remains to address knowledge gaps and we encourage the continued submission of health equity-focused articles to *JAMIA*.

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