Special Section on Inclusive Digital Health: Notable Papers on Addressing Bias, Equity, and Literacy to Strengthen Health Systems

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Summary

Objective: To summarize significant research contributions on addressing bias, equity, and literacy in health delivery systems published in 2021.

Methods: An extensive search using PubMed and Scopus was conducted to identify peer-reviewed articles published in 2021 that examined ways that informatics methods, approaches, and tools could address bias, equity, and literacy in health systems and care delivery processes. The selection process comprised three steps: (1) 15 candidate best papers were first selected by the two section editors; (2) external reviewers from internationally renowned research teams reviewed each candidate best paper; and (3) the final selection of three best papers was conducted by the editorial committee of the Yearbook.

Results: Selected best papers represent studies that characterized significant challenges facing biomedical informatics with respect to equity and practices that support equity and literacy in the design of health information systems. Selected papers represent the full spectrum of this year's yearbook theme. In general, papers identified in the search fell into one of the following categories: (1) descriptive accounts of algorithmic bias in medical software or machine learning approaches; (2) enabling health information systems to appropriately encode for gender identity and sex; (3) approaches to support health literacy among individuals who interact with information systems and mobile applications; and (4) approaches to engage diverse populations in the use of health information systems and the biomedical informatics workforce.

Conclusion: Although the selected papers are notable, our collective efforts as a biomedical informatics community to address equity, literacy, and bias remain nascent. More work is needed to ensure health information systems are just in their use of advanced computing approaches and all persons have equal access to health care and informatics tools.

1   Introduction

The global COVID-19 pandemic highlighted multiple inequities in access to health and well-being as well as delivery of health care. In the United States, the pandemic exposed systematic inequities with respect to health and well-being for minority populations, including Americans with brown skin tones as well as Native American peoples [1, 2]. Systematic racism and inequities in the social determinants of health resulted in significant, disproportionate burden of SARS-CoV-2 infections and COVID-19 hospitalizations [3-5]. The same phenomenon was observed in Canada [6] and Israel [7]. Moreover, although more heavily burdened with respect to morbidity and mortality due to COVID-19, ethnic minority populations were less likely to receive COVID-19 vaccines [7].

Although the pandemic brought systematic inequities to the forefront in the media and in academic circles, limited access to health and social justice have been priorities for the World Health Organization for many years. It is precisely for this reason that the International Medical Informatics Association (IMIA) Yearbook Selection Committee chose Inclusive Digital Health as this year's theme. The special section of the Yearbook focuses on calling out recent, high-quality publications that examine and/or advance our understanding of bias, equity, and literacy with respect to health information technologies and systems.

2   Methods

A health sciences librarian performed literature searches using PubMed and Scopus in January 2022. Queries were developed to broadly search biomedical and non-biomedical journals for articles pertaining to

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information systems as well as at least one of the three sub-domains for this year's theme: bias, equity, and literacy. Both controlled vocabulary terms (e.g., MeSH) and text words were used. We employed Boolean logic to identify articles published in English language between January 1, 2021 and December 31, 2021, that contained at least one information science term *and* one thematic term. The full queries are included as Appendix A.

Information retrieval yielded 979 articles (622 from PubMed; 357 from Scopus). Using Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia), search results were merged (229 duplicates removed), and the editors performed initial screening of titles and abstracts. Screening removed 605 studies that did not pertain to the theme. Both editors reviewed the 144 remaining articles and categorized them into three groups (accept, discuss, and discard) based on their innovativeness, scientific and/or practical impact, and methodological quality. Reasons for exclusion included descriptive review article or commentary/editorial (47 articles); lack of focus on diversity, equity, or inclusion (19 articles); observational health literacy study (19 articles); and prototype or feasibility study (13 articles).

This process yielded 15 articles as candidate best papers. In accordance with the IMIA Yearbook selection process, the 15 candidate best papers were further evaluated by the two section editors, the chief editor of the section, and by additional external reviewers (at least four reviewers per paper) with expertise in medical and/or public health informatics.

3 Results

The search yielded a large corpus of papers related to the broad subtopics included in this year's theme. Although many identified papers examined aspects of equity, literacy or bias, a much smaller set of articles focused on these topics in the context of biomedical informatics. Furthermore, we found several strong papers on the role of health informatics in addressing the topics of bias, equity, and literacy were editorials or opinion pieces, which are excluded from the selection of the Best Papers. Very few articles in the corpus

pertained to experiments in which innovations in addressing these topics were tested or real-world evidence from electronic health records were used to advance health system improvements in bias, equity, and/or literacy.

Candidate papers generally fell into one of the following categories: (1) descriptive accounts of algorithmic bias in medical software or machine learning approaches; (2) enabling health information systems to appropriately encode for gender identity and sex; (3) approaches to support health literacy among individuals who interact with information systems and mobile applications; and (4) approaches to engage diverse populations in the use of health information systems and the biomedical informatics workforce. Here we describe each category with many candidate papers deserving of an honorable mention even if they were not selected as a best paper.

3.1 Algorithmic Bias

Algorithmic bias is often defined in the context of artificial intelligence and machine learning programs and systems, but the concept applies to a broad array of applications in biomedical and health informatics. As such, one excellent definition is offered by Panch *et al*., "the instances when the application of an algorithm compounds existing inequities in socioeconomic status, race, ethnic background, religion, gender, disability or sexual orientation to amplify them and adversely impact inequities in health systems" [8]. Braun *et al.,* [9] investigated the racial bias inherent in algorithms for determining kidney function. This issue has been a focus of concern for nephrologists, renal epidemiologists, and biostatisticians especially since it concerns the diagnosis and staging of chronic kidney disease. Another area of concern is the appropriate and accurate representation of race in the health care record. This was addressed in de Souza *et al.*, where race and skin color are used for political ends but can be used to measure health outcomes as well [10]. Finally, Kordzadeh and Ghasemaghaei propose a new model for examining algorithmic bias, proposing that "…algorithmic bias can affect fairness perceptions and technology-related behaviours such as machine-generated recommendation acceptance, algorithm appreciation, and system adoption" [11].

3.2 Gender and Sex

It is becoming increasingly recognized that gender and sex are not interchangeable terms, although they are often used this way, with the unfortunate default to the term "sex" as a dichotomous feature (male/female) in medical records. As a result, this approach to characterizing gender, which is more closely related to how individuals self-identify and exists along a continuum representing many variations between the two poles of male and female. Five articles in our search deserve an honorable mention for their focus on improving representation of gender, sex, and sexual orientation (GSSO) in health records. The article by Antonio, et al. describes the creation and specifics of a seven-point plan to address the shortcomings of the current system of GSSO representation in Canadian health records [12]. Pho *et al.*, surveyed trans-gender and gender-diverse people to understand their patterns of seeking online information relating to human papillomavirus vaccination as well as general health literacy [13]. The assignment of gender at birth has attracted attention from clinicians as well as informaticians, because it has important implications for future clinical care, but also the use of obstetric and other health records for research and surveillance. Thompson *et al.*, addressed this issue in their work, which calls for improved provider literacy as gender is assigned at birth and how gender is used in the clinical record after assignment [14]. In addition to these efforts, there is considerable work on gender inclusivity and equity in healthcare. Bright *et al.*, proposed a plan to improve the representation of women in biomedical and health informatics [15], and Geana *et al.*, described informatics interventions to improve the health literacy of incarcerated women [16].

3.3 Health Literacy and Information Access

Research into, and the practice of improving, health literacy is clearly in the domain of biomedical and health informatics. We are an information-centric profession by definition, and we are called to work closely with clinicians and health information specialists such

as health educators and librarians to create and implement effective models and approaches of providing health information to patients, families, and the public at large. Our search resulted in the retrieval of five excellent examples of where informatics fits into this enterprise. Geana focused on improving health literacy of women in prison, particularly to prepare them for life after release [16]. The paper further described a new intervention, SHE WOMEN, which is an mHealth application designed to provide a "…rich, comprehensive, engaging, and scalable online training solution tailored for women leaving jail, while concomitantly being able to collect usability data for evaluation and feedback". The pilot study provides a model for this kind of application to deliver effective health information and improve health literacy, even beyond those who are incarcerated and preparing for life outside prison. Kostagiolas et al., pursued a different, yet important avenue at the intersection of health literacy and informatics that focuses on information seeking behavior [17]. They call for empowering clinical librarians to lead the effort to train patients to search for health information and to evaluate the information they find. Another study that sought to investigate health information seeking behavior focused on transgender and gender-diverse people and correlated this behavior with overall literacy [13]. Reuland et al., looked at the modalities used by low-income Latino immigrant parents, a particularly important group because of the intersection of language, health literacy, overall literacy, immigration status, and parenthood [18]. They found that our assumptions that this population would use mHealth interventions and modalities are challenged by comparatively low use of email, but particularly by the markedly low use (10% or their respondents) of mHealth interventions in general. Finally, Wang et al., evaluated a virtual counselor intervention to capture family medical history in a safety net population [19].

3.4 Race and Cultural Diversity

The largest number of articles retrieved by our search revealed a focus on diversity, especially racial and cultural. There was considerable overlap between this cate-

gory and the previous three, as might be expected; this overlap reflects the intersectionality that those working in diversity, inclusion, and equity identify in their work every day. In addition to previously cited studies, others in our retrieved document set examined racial and cultural diversity from a number of different perspectives. For example, Chunara et al., reported on a cohort study of disparities in telehealth access and use experienced during the COVID-19 pandemic in New York City [20]. They found that these disparities reflected similar disparities seen in access to healthcare in general in this population. Another study examined differences between Black and white prostate and bladder cancer patients in self-reporting outcomes. In their study, Samuel et al., [21] found that both groups were satisfied with electronic patient-reported systems, indicating that this type of modality would be a possible way to reduce disparities in follow up in these patients. Siegal et al., measured differences in racial disparities and neighborhood deprivation using geographic information system analysis in an effort to evaluate the effects of place-based initiatives before and during the COVID-19 pandemic [22]. They took a syndemic approach, considering structural racism in their investigation, and found that place-based initiatives were an approach to managing the effects of the pandemic. Finally, Virgil-Hayes et al., designed a novel behavioral mHealth application that considered the needs of Native American youth in the Southwest of the United States [23]. Taking a

robust computer-supported cooperative work approach with Native American youth who were candidate users, they demonstrated an approach to developing such applications in marginalized populations.

The papers selected by the section editors in consultation with the editorial board as best papers are summarized in Table 1. Final selection was based on these criteria: (1) reviewer ratings and comments; (2) equity across nation and world region; and (3) content balance across the three subtopics. Some topics had more candidate papers than others, and the editors felt that all three topics should be represented in the special section. A content summary of the selected best papers can be found in Appendix B of this synopsis.

4 Conclusions and Outlook

The best papers on inclusive digital health in 2021 represent only a fraction of the strong scientific articles relevant to this topic published before and after this synopsis. The topic came to the forefront due to glaring inequities in morbidity and mortality during the COVID-19 pandemic, but the work to make health delivery systems, supported by robust information systems, inclusive has only begun. We recognize that more evidence and leadership will be necessary to develop and implement best practices in support of health and well-being for all persons across the globe.

Table 1 Best paper selection of articles for the IMIA Yearbook of Medical Informatics 2022 in the special section "Inclusive Digital Health: Addressing Bias, Equity, and Literacy to Strengthen Health Systems". The articles are listed in alphabetical order of the first author's surname.

Section
Inclusive Digital Health: Addressing Bias, Equity, and Literacy to Strengthen Health Systems
▪ Braun L, Wentz A, Baker R, Richardson E, Tsai J. Racialized algorithms for kidney function: Erasing social experience. Soc Sci Med 2021 Jan;268:113548.
▪ Pho AT, Bakken S, Lunn MR, Lubensky ME, Flentje A, Dastur Z, Obedin-Maliver J. Online health information seeking, health literacy, and human papillomavirus vaccination among transgender and gender-diverse people. J Am Med Inform Assoc 2022 Jan 12;29(2):285-95.
▪ Vigil-Hayes M, Collier AF, Hagemann S, Castillo G, Mikkelson K, Dingman J, Muñoz A, Luther J, McLaughlin A. Integrating Cultural Relevance into a Behavioral mHealth Intervention for Native American Youth. Proc ACM Hum Comput Interact 2021 Apr;5(CSCW1):165.

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2. Alcendor DJ. Racial Disparities-Associated COVID-19 Mortality among Minority Populations in the US. J Clin Med 2020 Jul 30;9(8):2442.

3. Dixon BE, Grannis SJ, Lembcke LR, Valvi N, Roberts AR, Embi PJ. The synchronicity of COVID-19 disparities: Statewide epidemiologic trends in SARS-CoV-2 morbidity, hospitalization, and mortality among racial minorities and in rural America. PLoS One 2021 Jul 23;16(7):e0255063.

4. Hansotte E, Bowman E, Gibson PJ, Dixon BE, Madden VR, Caine VA. Supporting Health Equity Through Data-Driven Decision-Making: A Local Health Department Response to COVID-19. Am J Public Health 2021 Oct;111(S3):S197-S200.

5. Romano SD, Blackstock AJ, Taylor EV, El Burai Felix S, Adjei S, Singleton CM, Fuld J, et al. Trends in Racial and Ethnic Disparities in COVID-19 Hospitalizations, by Region - United States, March-December 2020. MMWR Morb Mortal Wkly Rep 2021 Apr 16;70(15):560-5.

6. Mishra S, Ma H, Moloney G, Yiu KCY, Darvin D, Landsman D, et al; COVID-19 Heterogeneity Research Group. Increasing concentration of COVID-19 by socioeconomic determinants and geography in Toronto, Canada: an observational study. Ann Epidemiol 2022 Jan;65:84-92.

7. Luxenburg O, Singer C, Myers V, Wilf-Miron R, Saban M. Sociodemographic disparities in COVID-19 burden: changing patterns over four pandemic waves in Israel. J Epidemiol Community Health 2022 Apr 26:jech-2021-217993.

8. Panch T, Mattie H, Atun R. Artificial intelligence and algorithmic bias: implications for health systems. J Glob Health 2019 Dec;9(2):010318.

9. Braun L, Wentz A, Baker R, Richardson E, Tsai J. Racialized algorithms for kidney function: Erasing social experience. Soc Sci Med 2021 Jan;268:113548.

10. de Souza IM, Hughes GD, van Wyk BE, Mathews V, de Araújo EM. Comparative Analysis of the Constitution and Implementation of Race/Skin Color Field in Health Information Systems: Brazil and South Africa. J Racial Ethn Health Disparities 2021 Apr;8(2):350-62.

11. Kordzadeh N, Ghasemaghaei M. Algorithmic bias: review, synthesis, and future research directions. Eur J Inf Syst 2022;31:388-409.

12. Antonio M, Lau F, Davison K, Devor A, Queen R, Courtney K. Toward an inclusive digital health system for sexual and gender minorities in Canada. J Am Med Inform Assoc 2022 Jan 12;29(2):379-84.

13. Pho AT, Bakken S, Lunn MR, Lubensky ME, Flentje A, Dastur Z, et al. Online health information seeking, health literacy, and human papillomavirus vaccination among transgender and gender-diverse people. J Am Med Inform Assoc 2022 Jan 12;29(2):285-95.

14. Thompson HM, Kronk CA, Feasley K, Pachwicewicz P, Karnik NS. Implementation of Gender Identity and Assigned Sex at Birth Data Collection in Electronic Health Records: Where Are We Now? Int J Environ Res Public Health 2021 Jun 19;18(12):6599.

15. Bright TJ, Williams KS, Rajamani S, Tiase VL, Senathirajah Y, Hebert C, et al. Making the case for workforce diversity in biomedical informatics to help achieve equity-centered care: a look at the AMIA First Look Program. J Am Med Inform Assoc 2021 Dec 28;29(1):171-5.

16. Geana MV, Anderson S, Lipnicky A, Wickliffe JL, Ramaswamy M. Managing Technology, Content, and User Experience: An mHealth Intervention to Improve Women's Health Literacy after Incarceration. J Health Care Poor Underserved 2021;32:106-27.

17. Kostagiolas P, Koumbouli M, Theodorou P, Stamou S. Investigation of the Information-Seeking Behavior of Hospitalized Patients at the General Hospital of Corfu. J Hosp Librariansh 2021;21(1):36-60.

18. Reuland CJ, Godage SK, Wu L, Valenzuela-Araujo D, Cortez JD, Polk S, et al. Information and Communication Technology Access and Use Among Low-Income Latino Immigrant Parents. Matern Child Health J 2021 Dec;25(12):1807-13.

19. Wang C, Paasche-Orlow MK, Bowen DJ, Cabral H, Winter MR, Norkunas Cunningham T, et al. Utility of a virtual counselor (VICKY) to collect family health histories among vulnerable patient populations: A randomized controlled trial. Patient Educ Couns 2021 May;104(5):979-88.

20. Chunara R, Zhao Y, Chen J, Lawrence K, Testa PA, Nov O, et al. Telemedicine and healthcare disparities: a cohort study in a large healthcare system in New York City during COVID-19. J Am Med Inform Assoc 2021 Jan 15;28(1):33-41.

21. Samuel CA, Smith AB, Elkins W, Richmond J, Mahbooba Z, Basch E, et al. Racial differences in user experiences and perceived value of electronic symptom monitoring in a cohort of black and white bladder and prostate cancer patients. Qual Life Res 2021 Nov;30(11):3213-27.

22. Siegal R, Cooper H, Capers T, Kilmer RP, Cook JR, Garo L. Using geographic information systems to inform the public health response to COVID-19 and structural racism: The role of place-based initiatives. J Community Psychol 2022 Aug;50(6):2611-29.

23. Vigil-Hayes M, Collier AF, Hagemann S, Castillo G, Mikkelson K, Dingman J, et al. Integrating Cultural Relevance into a Behavioral mHealth Intervention for Native American Youth. Proc ACM Hum Comput Interact 2021 Apr;5(CSCW1):165.

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Appendix: Search Queries Constructed for PubMed and Scopus to Identify Candidate Papers for Review

PubMed

("Informatics"[Majr] OR "Information Systems"[majr] OR informatics[tiab] OR "information systems"[tiab] OR "information system"[tiab] OR "digital health"[tiab] OR "eHealth"[tiab] or "mHealth"[tiab])
AND
("Health Literacy"[Mesh] OR "Prejudice"[Mesh] OR "Bias, Implicit"[Mesh] OR "Cultural Diversity"[Mesh] OR "Health Equity"[tiab] OR "algorithmic bias"[tiab] or "algorithmic fairness"[tiab] or "Diversity"[tiab] OR "racism"[tiab] or "Health Literacy"[tiab] OR "Prejudice"[tiab] or "implicit bias"[tiab] or "health inequity"[tiab] OR "health inequities"[tiab] OR "health disparity"[tiab] OR "health disparities"[tiab])
AND NOT ("preprint"[Publication Type] OR editorial[Publication Type] OR "letter"[Publication Type] OR "news"[Publication Type])
Limits: English, Abstracts-included
Scopus

TITLE-ABS ((informatics OR "information systems" OR "information system" OR "digital health" OR "eHealth" OR "mHealth") AND ("Health Equity" OR "algorithmic bias" OR "algorithmic fairness" OR "Diversity" OR "racism" OR "Health Literacy" OR "Prejudice" OR "implicit bias" OR "health inequity" OR "health inequities" OR "health disparity" OR "health disparities")) AND (EXCLUDE(DOC-TYPE, "cp") OR EXCLUDE (DOCTYPE, "ch") OR EXCLUDE (DOCTYPE, "ed") OR EXCLUDE (DOCTYPE, "cr") OR EXCLUDE (DOCTYPE, "er") OR EXCLUDE (DOCTYPE, "bk")) AND (LIMIT-TO (PUBYEAR, 2022) OR LIMIT-TO (PUBYEAR, 2021)) AND (LIMIT-TO (LANGUAGE, "English"))
Searches run on 1/12/2022