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Inclusive Digital Health

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Summary

Objectives: To introduce the 2022 International Medical Informatics Association (IMIA) Yearbook by the editors.

Methods: The editorial provides an introduction and overview to the 2022 IMIA Yearbook whose special topic is "Inclusive Digital Health: Addressing Equity, Literacy, and Bias for Resilient Health Systems". The special topic, survey papers, section editor synopses and some best papers are discussed. The sections' changes in the Yearbook Editorial Committee are also described.

Results: As shown in the previous edition, health informatics in the context of a global pandemic has led to the development of ways to collect, standardize, disseminate and reuse data worldwide. The Corona Virus Disease 2019 (COVID-19) pandemic has demonstrated the need for timely, reliable, open, and globally available information to support decision making. It has also highlighted the need to address social inequities and disparities in access to care across communities. This edition of the Yearbook acknowledges the fact that much work has been done to study health equity in recent years in the various fields of health informatics research.

Conclusion: There is a strong desire to better consider disparities between populations to avoid biases being induced in Artificial Intelligence algorithms in particular. Telemedicine and m-health must be more inclusive for people with disabilities or living in isolated geographical areas.

1 Medical Informatics as a Support for Reducing Health Inequalities and Healthcare Disparities

The Corona Virus Disease 2019 (COVID-19) pandemic has been a particularly powerful and painful indicator of social inequalities, especially in access to health care. As the focus of 2021 Yearbook was "Managing Pandemics with Health Informatics – Successes and Challenges" [1], this year's theme continues with a closer look at health equity in our health systems. Indeed, social determinants of health have a major impact on mortality and morbidity from the pandemic, making fragile populations more vulnerable [2]. Prior to the COVID-19 health crisis, Ebola had already highlighted the importance of developing resilient information systems, i.e. capable of guaranteeing the care and good health of all, even in times of crisis or afterwards, by adapting to the situation [3]. In the meantime, the increase in migration due to war or problems resulting from climate change also revealed issues that the scientific community must address. In particular, Chris Lehmann saw an urgent need for action by the medical informatics researchers to improve international information exchange to facilitate the care of displaced populations [4].

In this frame, the theme of the 31st edition of the International Medical Informatics Association (IMIA) Yearbook is "Inclusive Digital Health: Addressing Equity, Literacy, and Bias for Resilient Health Systems". The Special Section provides a review of significant papers for 2021 that focus on health equity and informatics tools. Section editors Brian Dixon and John Holmes found studies that characterized significant challenges facing biomedical informatics with respect to practices that support equity and literacy in the design of health information systems [5]. Challenges are further addressed in the survey paper where Koehle et al. stress that "*it may be easy to look at the current health equity landscape as irreparable, having been built on hundreds of years of oppression, marginalization, and discrimination. In this work, we have emphasized collaboration with user and patient groups to define priorities, ensure accessibility and localization, and consider risks in development and utilization of digital health tools*" [6].

2 Highlights of the 31st Edition of the IMIA Yearbook

We are proud to include a chapter on Education by Edward (Ted) H. Shortliffe, who kindly accepted the invitation of Sabine Koch (IMIA past president) to write a paper adapted from the presentation he gave at the IMIA François Grémy Award of Excellence ceremony during Medinfo2021 [7]. Be sure to read this chapter and the International Academy of Health Sciences Informatics (IAHSI) paper by William (Bill) Hersh, the Academy's President [8]. The History of Medical Informatics chapter by Casimir Kulikowski [9] provides an analysis of early papers on ethics in clinical decision making relevant to the equity, fairness, and inclusiveness desired by today's digital health systems.

In this 31st edition of the IMIA Yearbook, you will also find valuable contributions from IMIA Working Groups related to the significant topic of inclusive digital health (to name a few: the need for new generations of electronic health records, the drivers of inequity in healthcare, the challenges of inclusive health information technology for vulnerable older adults, open source projects, the comparison of several digital primary care systems that can promote system equity…), showing the opportunity to use lessons learned from COVID-19 in the development of digital health, and how they can contribute to making healthcare systems more resilient, accessible and equitable.

The Research paper by Tiffany Veinot *et al.* [10] also a co-author of a best paper selected in the Consumer Health Informatics section [11], concentrates on nine health informatics studies with a focus on equity in the U.S. and Canada (disparities related to age, disability or chronic illness, gender/sex, place of residence, race/ethnicity, sexual orientation, and socioeconomic status) from which they derive a framework of four considerations for advancing health equity in informatics: PRAXIS (Participation, Representation, Appropriate methods and interventions, conteXtualization and structural competence, and Investigation of Systematic differences).

In the Bioinformatics and Translational Informatics (BTI) section's best papers, co-editors Mary Lauren Benton and Scott McGrath observed several important trends, including the use of deep learning approaches to analyze diverse data types, the development of integrative and web-accessible bioinformatics pipelines, and a continued focus on the power of individual genome sequencing for precision health [12]. The survey paper for BTI by Tang *et al.* addresses how equity and inclusion should be incorporated in every step of bioinformatics projects [13]. More work needs to be done in computational biology to include specific groups of patients in algorithms and avoid algorithm bias, and the amount of data available continues to be a challenge.

The Clinical Research Informatics (CRI) section also named some of the informatics challenges to handling data. Editors Christel Daniel, Dipak Kalra and Xavier Tannier

wrote that the increasing scale and scope of biomedical data is not only generating enormous opportunities for improving health outcomes but also raises new challenges ranging from data acquisition and storage to data analysis and utilization [14]. In the CRI survey paper, Kargl *et al.* addressed the challenges of artificial intelligence (AI) in clinical research and biobanking. The authors emphasized the need for an ethical-mindfulness and proportionate approach to AI in biomedical research. They specifically reveal the need for AI ethics research focused on understanding and resolving practical problems arising from the use of AI in science and society [15].

With a focus on health equity in decision support, Stipelman *et al.* in their Decision Support (DS) survey for 2021 [16] emphasized that Clinical Decision Support (CDS) tools may improve health equity and outcomes for patients who face disparities. The authors underscored the need for high-quality analyses of CDS-associated health outcomes, reporting of user-centered design and implementation strategies used in low-resource settings, and methods to disseminate CDSs created to improve health equity. DS co-editors Damian Borbolla and Tiago Colicchio also found a wide variety of research in the field this year as well as continued interest in CDS to help in cases of COVID-19 in the pandemic [17]. This year's best paper selection highlighted innovation in the CDS evaluation process, alert fatigue, and a more traditional approach to measuring the efficacy and efficiency of CDS alerts.

The Human Factors and Organizational Issues (HFOI) section, co-editors Yalini Senathisrajah and Anthony Solomonides chose four papers that were clearly outstanding and help advance the field of human factors [18]. The papers examine novel and important topics such as the nature of human-machine interaction behavior and norms, the use of social media-based design for an electronic health record, and emerging topics such as brain-computer interfaces, thematic development of electronic health records and usability techniques, and condition-focused patient facing tools.

The Consumer Health and Informatics (CHI) section also included papers on the coronavirus but interestingly, section editors

Annie Lau and Pascal Staccini discovered that the COVID-19 topic was retrieved without any use of the term in the query [19]. Selected papers for CHI illustrate an area of inclusiveness that should be acknowledged, such as sexual orientation and methods to reach people in lower income countries. Also, the topic of disability, deafness, in particular, needs to be acknowledged especially with the rise in telehealth - how would this community receive care when seeking medical help relies mainly on the telephone?

Check out the survey paper for CHI that addresses some progress in health care opportunities for racial and ethnic minorities [20]. Valdez and Rogers conclude that future research should utilize community engagement strategies to design interventions that are attune to multiple racial and ethnic minoritized populations across geographic regions in addition to numerous intersectional identities and multiple co-morbidities. In the Keynote paper, co-authored by Valdez, Ancker, and Veinot [21], you will find five "provocations" related to health informatics as a starting point for building a more conscientious informatics practice. The authors assert that radical changes in current practice will enhance patient-centered approaches, especially for marginalized communities.

Read the comprehensive survey paper by Neil Sarkar, who reviewed 256 articles published between 2018 and 2021 related to Health Information Exchange (HIE) issues [22]. Of the seven categories of works he identified, one is dedicated to health disparities and summarizes ten papers addressing health literacy and equity. Of the three best papers selected this year from a total of 15 candidates described in the synopsis by Eta S. Berner and Meryl Bloomrosen, the HIE section co-editors [23], two papers are relevant to the issues of this year's special theme. Nsaghurwe *et al.* describe in great detail a five-step approach to HIE development in Tanzania that may be useful to many other countries developing their national health information systems [24]. Chen *et al.*, showed significant disparities in the ability of hospitals to adopt telehealth depending on their geographic location [25].

The co-editors of the Clinical Information Systems (CIS) section, Werner Hackl and Alexander Hörbst, did not identify any

real novelties in the themes addressed in the 10 candidate articles selected this year compared to recent years [26]. The work by Harris *et al.*, which is one of the two best papers selected in this section, conducted a large study in five different countries in diverse geographic locations to investigate the potential utility of mobile consultation for health care delivery [27]. The authors emphasized that low- and middle-income countries are motivated to embrace this digital shift, but that this requires addressing the inevitable technical and privacy issues and a robust health information system that is essential to ensure continuity of care. Check out the survey paper of the CIS section which focuses on patient experience and how it is defined and captured in eHealth [28]. The authors reviewed 44 papers, and concluded that patient experience is complex and multifaceted, requiring additional research to better understand this phenomenon.

The survey paper of the Knowledge and Representation Management (KRM) section presents a selection of 22 papers from 2020 and 2021 focusing on contributions to health inclusivity and bias [29]. The author, Janna Hastings, grouped these works according to their contribution, namely: (i) semantic resources developed to represent knowledge about health inequalities and biases, (ii) efforts to enable data sharing across different health information systems, communities, cultures, and disciplines while ensuring data privacy, and (iii) solutions that take into account the importance of reducing biases that exist in the data on which medical AI algorithms are trained in order to achieve inclusiveness. One of the best papers in the KRM section details the new version of the International Classification of Diseases, ICD-11 [30]. Among the many changes from the previous version is the introduction of a new chapter entitled "Conditions related to sexual health" that includes gender dysphoria, which is much less stigmatizing in its description than before. This notion is now labelled "Gender incongruence" contrary to the way it was done in ICD-10, where the corresponding concept appeared as a "Gender identity disorder, unspecified" in the chapter "Mental and behavioural disorders", thus considering it as a disease [31]. The other 14 candidate best papers described by co-editors Licong

Cui and Jean Charlet of the KRM section synopsis did not specifically address issues related to this year's theme [32], nor did the contributions listed afterward.

The survey paper of the Signals, Sensors, and Imaging Informatics (SSII) section presents a systematic review of 223 articles related to automated computational segmentation of the lung and its lobes [33]. The authors classified the different works according to the types of methods developed, namely those based on: (i) thresholding, (ii) region, (iii) shape or pattern, (iv) traditional machine learning, (v) deep learning, and finally those (iv) guided by neighborhood anatomy. Twenty public datasets used in these studies are also listed. SSII co-editors Christian Baumgartner and Thomas Deserno wrote a synopsis featuring their selection of the best papers of 2021 in which an emerging trend was notably observed, namely the combination of signal processing and sensor technologies, and where the development of deep learning approaches for medical image processing remains substantial [34].

The synopsis of the Public Health and Epidemiology Informatics (PHEI) section presents the 11 best papers they nominated [35]. Georgeta Bordea and Gayo Diallo, the co-editors of this section, noted in particular that some of these works have focused on data that is not considered health data per se, such as that from mobile apps and social media. Swertz *et al.,* wrote the PHEI survey paper on existing cohort and real-world data catalogues [36]. The authors provided recommendations for standardization efforts that should be undertaken to enable sharing of these catalogues within the scientific community.

The Natural Language Processing (NLP) survey paper from Aramaki *et al.* focuses on practical clinical applications of NLP methods [37]. The authors listed NLP-based systems implemented in ten hospital departments to illustrate what they call "bedside applications", while specifying the different types of NLP tasks addressed. Check out the NLP synopsis by co-editors Natalia Grabar and Cyril Grouin, who conducted a thorough analysis of the 2021 biomedical NLP literature [38]. They noticed that transformer-based models are extensively studied, that there is a lot of work on dedicated applica-

tions such as COVID-19 and mental health, and still many papers presenting information extraction methods.

Last but not least, read the well-documented Cancer Informatics (CI) survey paper from Chaunzwa *et al.* related to the study and measure of disparities and bias in cancer incidence [39]. The authors reviewed clinical informatics studies related to cancer disparities published from 2018 to 2021, with a focus on domains such as real-world data analysis, natural language processing, radiomics, genomics, proteomics, metabolomics and metagenomics. They concluded that care will be needed to ensure that algorithmic bias does not magnify existing disparities. "*Real-world data yields important insights into the conduct of clinical trials and registries*", concluded Debra Patt and Jeremy Warner, co-editors of the CI section, in their review of scientific contributions published in 2021 on topics related to cancer informatics [40]. Indeed, the two selected best papers deal with complementary aspects of real-world databases and registries for population-level research in cancer [41, 42]. Women, the elderly, and racial or ethnic minorities have been relatively excluded from cancer clinical trials, and this trend appears to be worsening over time, as studied by Riaz *et al.* [43]. Liu *et al.* determined that relaxing trial eligibility criteria would result in small changes in hazard ratios for critical outcomes such as overall survival [41]. This has major implications for the future design of cancer clinical trials. Yang *et al.* assessed the prevalence of missing data in a very large cancer patient registry, and determined whether missing data was itself a prognostic factor [42]. The authors demonstrated the importance of metadata characteristics in the conduct and evaluation of real-world data registry studies. They note that "*Records with missing data were more prevalent among Black patients and patients from other racial and ethnic minority groups, which may reflect long-standing disparities in access to health care and cancer treatment*".

The 2023 special topic of the Yearbook will be: "Informatics for One Health". As we learn to live with COVID-19, we have come to realize that we can live differently. It is even essential to realize that we must do so at all costs if we want everyone to continue to

live with dignity and equity. Indeed, climate change has a major impact on our environment and on the lives of animals and humans. It is therefore essential to consider and ensure the health of all these components, not only our own, as already underlined in this year's Yearbook [44]. As a recent article by Gray points out, health informatics has a role to play in addressing climate-related global health issues [45]. These observations led us to choose next year's theme in order to identify and highlight the contributions of research in medical informatics in the area of *one health* to encourage our scientific community to take hold of the subject.

3 Changes in the Yearbook Editorial Team

We are pleased to welcome Licong Cui, assistant professor at the University of Texas Health Science Center (Houston, USA), as a new section editor of the KRM section. Scott McGrath, program manager for CITRIS Health's ACTIVATE program at the University of California Berkeley (California, USA) and Mary Lauren Benton, assistant professor in the Department of Computer Science at Baylor University (Texas, USA), are the new editors of the BTI section. Anthony Solomonides, Program Director for Outcomes Research and Biomedical Informatics at NorthShore University (Illinois, USA), is a new editor for the HFOI section. For the CRI section, we welcome Xavier Tannier, professor at Sorbonne Université (Paris, France).

On the departure side, Alexander Hörbst, professor at the Department Medical Technologies of the Management Center Innsbruck (Austria), who served as an editor of the Clinical Information Systems section from 2018 to 2022 is leaving the editorial team in 2023. We thank him warmly for his valuable contribution to the IMIA Yearbook. We also thank Damian Borbolla, assistant professor at the University of Utah (Utah, USA) and Tiago Colicchio, assistant professor at the University of Alabama at Birmingham (Alabama, USA) for their work on DS this year, and we are honored to welcome

(back) Christoph U. Lehmann, professor at University of Texas Southwestern, Dallas (Texas, USA) and Vignesh Subbian, assistant professor at the University of Arizona, Tucson (Arizona, USA) as new DS editors next year. Christel Daniel, who has been co-editor of the CRI section since 2012, is leaving her position as co-editor and we thank her so much for her valuable work for the past 10 years!

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