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Title

Role of Health Information Technology in Addressing Health Disparities

Permalink

<https://escholarship.org/uc/item/7t02148x>

Journal

Medical Care, 57(Suppl 2)

ISSN

0025-7079

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Publication Date

2019-06-01

DOI

10.1097/mlr.0000000000001092

Peer reviewed



Published in final edited form as:

Med Care. 2019 June ; 57(Suppl 6 2): S115–S120. doi:10.1097/MLR.0000000000001092.

Role of Health Information Technology in Addressing Health Disparities: Patient, Clinician, and System Perspectives

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Abstract

Over the last decade, health information technology (IT) has dramatically transformed medical practice in the United States. On May 11-12, 2017, the National Institute on Minority Health and Health Disparities (NIMHD), in partnership with the National Science Foundation and the National Health IT Collaborative for the Underserved, convened a scientific workshop, “Addressing Health Disparities with Health Information Technology,” with the goal of ensuring that future research guides potential health IT initiative to address the needs of health disparities populations.

The workshop examined patient, clinician, and system perspectives on the potential role of health IT in addressing health disparities. Attendees were asked to identify and discuss various health IT challenges that confront underserved communities and propose innovative strategies to address them, and to involve these communities in this process. Community engagement, cultural competency, and patient-centered care were highlighted as key to improving health equity, as well as to promoting scalable, sustainable, and effective health IT interventions. Participants noted the need for more research on how health IT can be used to evaluate and address social determinants of health. Expanding public-private partnerships was emphasized, as was the importance of clinicians and IT developers partnering and using novel methods to learn how to improve healthcare decision-making. Finally, to advance health IT and promote health equity, it will be

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Disclaimer: The findings and conclusions in this paper are those of the authors and do not necessarily represent the official position of the National Institutes of Health.

No conflict of interests from authors are reported.

necessary to record and capture health disparity data using standardized terminology, and to continuously identify system-level deficiencies and biases.

Introduction

Recent advances in health information technology (IT) hold great promise for improving health outcomes. Health IT innovations can give care providers more detailed information about their patients, enabling more precise, targeted treatment regimens. Patients also increasingly use IT to track and manage their own health, and to participate in shared decision-making, although a substantial digital divide continues to characterize health IT use.¹ Given the persistence of health disparities, it is critical to ensure that the benefits of advances in health IT serve to reduce, rather than inadvertently exacerbate, such disparities.²

On May 11-12, 2017, the National Institute on Minority Health and Health Disparities (NIMHD) in partnership with the National Science Foundation and the National Health IT Collaborative for the Underserved, convened a scientific workshop: “Addressing Health Disparities with Health Information Technology.” This workshop brought together nearly 50 participants (see Appendix document, Supplemental Digital Content 1, <http://links.lww.com/MLR/B733> which includes the list of participants), including healthcare workers, researchers, and other stakeholders, to discuss how advances in health IT can serve to reduce health disparities. Attendees were asked to identify and discuss various health IT challenges that confront underserved communities, to propose innovative strategies to address them, and to find ways to involve members of these communities in this process. The overarching goal was to ensure that future research guides health IT initiative to address the needs of health disparities populations. Workshop discussions focused on increasing patient-, clinician- (i.e., health care team), and system-level approaches to using health IT to prevent and reduce health disparities. These approaches are not clear-cut categories, and approaches in one might apply to others. Key recommendations are summarized in this paper.

Patient-Level Perspectives on Reducing Health Disparities Using Health IT

Recommendation #1. Promote health IT research that addresses the scalability and sustainability of interventions to improve health equity.

Public health seeks to ensure that the benefits of medical advances are available to all, regardless of race/ethnicity or socioeconomic status. Historically, however, vulnerable communities have been slow to benefit from technological advances in health care.¹ The needs and interests of health disparities populations point to the types of data that are most important to collect, and the types of study designs and IT interventions most suitable to these populations.³ Therefore, it is critical that researchers engage with community members early in research processes, and study designs should reflect community concerns. Too often, underserved communities are seen as consumers of health care rather than as potential producers of tools to improve health. Research should reflect the needs, priorities, interests, and cultural context of the target population as it relates to the delivery of health

interventions. The inclusion of community voices in the development of new technologies is vital to ensure adoption.

Efforts to address disparities should reflect the experiences of the affected populations, and the methods for doing so should themselves be respectful of the needs and customs of those populations. Data should be collected in a way that is not disruptive, and researchers should provide results and feedback that are useful to patients. Researchers must overcome mistrust from populations/communities historically exposed to research misconduct (e.g., Tuskegee⁴). Encouraging the participation of affected communities by inviting community members' ideas and solutions is highly recommended. Effective interventions must also be designed to be scalable and sustainable in health disparities populations. For example, barbershop-based health intervention (a pharmacist in collaboration with a barber) proved to be effective in lowering high blood pressure among African American men.⁵ Planning for such interventions should involve culturally-appropriate strategies for dissemination and implementation, and involve stakeholders from the targeted community to identify resources in the targeted communities.

Recommendation #2. Adopt rapid-cycle, continuous evaluation and implementation of new developments in health IT to address social determinants of health.

To reduce health disparities, health IT must address social determinants of health (SDH) – the conditions in which people are born, grow, live, work, and age.⁶ These include, but are not limited to, factors such as socioeconomic status, education, the built environment, employment, social support networks, and access to health care. Social determinants such as food insecurity, social isolation, and financial stress significantly impact health. Linking with non-health social determinants will require strong interoperability across systems, including health care, mental health/substance use, foster care, housing, nutrition, etc.

Any IT-based approach to addressing health disparities must consider social determinants. Community-level data might provide insights into these determinants. Much can be inferred about a person's environment based on their ZIP code, which can guide the design of localized community-targeted interventions to address health disparities.⁷ Incorporating community-level data into electronic health records (EHR) will allow clinicians to provide care that is informed by knowledge about the patient's neighborhood.⁸ However, some patients in vulnerable communities thrive, and some in less vulnerable communities do not. Too little is known about the interplay between community characteristics and patient-reported social needs. Research is needed to assess which patient- versus community-level data is most useful to providers to decrease health disparities, understand community resiliency, and improve health outcomes. Furthermore, very little is known about which patient- or community-level social determinants are associated with specific health outcomes in specific patient populations. Research must address this knowledge gap.

Novel, rapid-cycle, continuous evaluation research is needed to explore optimal approaches to collecting, integrating, and using social determinants data to effectively guide clinical care. As social determinants of health screening tools are now being incorporated into EHRs, the ability to evaluate how social determinants affect health is increasing, and science should capitalize on this exciting opportunity. Moreover, effective Health IT evaluations

require implementation science methods. The rise of disparities is often due to differing implementation approaches.

Recommendation #3. Explore public-private and other partnerships to incentivize the creation and adoption of health IT to reduce health disparities.

Community engagement, trust building, and partnership are the foundations of successful health IT interventions to reduce disparities. Evidence is needed to determine how public-private partnerships could facilitate developing and using IT to enhance provider-patient interactions, and allow patients to self-report health data and participate in healthcare decisions.⁹ Research suggests that for such partnerships to succeed, authentic discussions of the objectives, roles, and expectations of all parties, along with potential conflicts of interest, are critical.¹⁰ All parties must be involved in a process of continuous learning and be willing to partner with others to meet the community's needs. It is more likely that such endeavors will succeed if patients feel fully engaged and respected and realize value from their experience with health IT. Partnerships with public, private, and philanthropic agencies could help leverage government efforts and widen the audience for information about the prevention and reduction of health disparities.

Designers, researchers, and clinicians should keep in mind that technology-based, health-promoting approaches need to function in real-life settings and appreciate the social context and physical environment in which IT is used. IT interfaces should provide feedback to users in ways that are useful to these users. Research is needed on the partnerships needed to ensure that IT interventions meet community members where they live.

Levels of patient engagement in health self-management vary, as many patients are busy working and/or caring for others. It is important to develop IT interventions and tools that can collect meaningful data without disrupting patients' daily lives. One promising area is the use of technologies, such as cell phones or other mobile devices, to collect self-reported health data (e.g., the Food and Drug Administration's MyStudies App). Improving communication with non-English speakers is another way that IT may be used to address health disparities.¹¹ Computerized translation products might increase health literacy, safety, and patient engagement among non-English speakers.

Clinician-Level Perspectives on Reducing Health Disparities Using Health IT

Recommendation 4: Improve coordination between IT users and IT developers; increase health IT training in primary care settings.

Clinician/patient involvement in development processes is essential if health IT applications are to be successful. Ideally, the IT designer and healthcare team will develop such products together.¹² Participatory, human-centered design allow clinicians and patients alike to take an active role in the development process.^{12,13} User involvement in health IT development yields higher clinician acceptance of applications.^{12,14,15} There are, however, challenges to achieving this in practice: lack of time, disagreement between clinician users, inability to

reach consensus, and clinicians' lack of necessary technical skill.^{12,14} These challenges must be considered and addressed.

With this in mind, incorporating diverse types of clinician/patient involvement and training in the conceptualization and development of IT interventions is recommended.¹² Further research into best practices for user involvement in the design of complex health IT systems may increase the success of future health IT projects,¹⁶ and thus improve how IT approaches impact health care and health outcomes. Such efforts should strive to promote evidence-based health care, enhance communication among the members of the healthcare team to identify gaps in care, and increase understanding of disparities. Training for researchers and clinicians might include instruction in how IT might be used to affect health disparities.

Clinicians are increasingly challenged by the need to keep up with the latest disease prevention, management, and treatment recommendations. For example, clinical decision support (CDS) systems can join information about evidence-based practices with digitized data on the patient's history, values, and preferences to guide and support personalized patient care.¹⁷ EHR-integrated CDS can reduce errors due to bias, as well as reduce misuse and overuse of medical services. As a result, increasing health IT training for clinicians, especially in primary care settings, is of critical importance.

Recommendation 5: Encourage mixed-methods and participatory approaches to evaluating which health information is most relevant to clinicians and patients to improve healthcare decision-making.

Implementing successful IT solutions in clinics serving communities with health disparities has met with design challenges,¹⁸ including variability by population in the use of IT. Researchers may achieve more useful results employing mixed methods that develop both qualitative and quantitative data.^{19,20} Qualitative methods can provide in-depth exploration of the underlying causes of inequities in IT adoption and impact. Quantitative methods can then document health outcome changes and improvements in quality of life or patient satisfaction. Such mixed methods may be essential to address disparities in digital literacy, culture competency, and limited English proficiency by guiding the most appropriate health IT interventions. More research is needed to better understand the utilization of qualitative methods vs. quantitative methods.

Participatory approaches to system development that engage physicians in designing new clinical IT tools²¹ have proven effective. Clinicians with experience in informatics can help build trust with skeptical users, leading to more participant engagement, which might then translate into more successful IT projects.²² More research is needed to determine whether and how such approaches work in diverse clinical settings.²³

System-Level Perspectives on Reducing Health Disparities Using Health IT

Recommendation 6: Identify practices, procedures, and programs that promote respect, trust, and equity in the design and implementation of data systems.

Three broad areas are important to the success of health IT initiatives in addressing health disparities: 1) design, implementation, and adoption of new technologies that can be

employed effectively in the intended cultural context; 2) data capture and protection; and 3) management of the system-level data ecosystem. Several challenges within and across individual health systems and networks must be addressed if EHRs and other IT are to contribute to reductions in health disparities.² Research is needed on strategies for addressing these challenges.

Health IT researchers and healthcare systems should build on lessons learned. For example, the certification process provided by the Office of the National Coordinator (ONC) for health IT (www.healthit.gov/) increased IT adoption and meaningful use among rural providers. The extent to which technology can be integrated into the workflow efficiently, effectively, and satisfactorily by clinical users is an area of concern for diverse practices²⁴ and healthcare systems.²⁵ The design of IT interventions must also account for clinician-patient communication.²⁶ For example, the employment of medical scribes to enter data into the EHR, has had a positive impact on physician and patient satisfaction, as well as on provider productivity.²⁷

The design and implementation of procedures, programs, and practices, including mobile health and telemedicine, that ameliorate health disparities can impact patient care, patient-physician interactions, and training.²⁸ For example, chronic disease management and outcome may require specific strategies aimed at narrowing inequality as part of their fundamental design.²⁹ Community involvement in design, implementation, and evaluation of such IT is recommended.³⁰

Recommendation #7: Standardize data collection in electronic health records and develop innovative technologies to capture new data on health disparities populations.

Innovative technologies that capture new data streams will be most effective if data collection methods are standardized.² The literature recommends which SDH data should be collected, but says little about the form such data should take, or on the data capture technologies and/or data protection methods needed to obtain such data in a way that can be used to address health disparities.

EHR data can be used to identify areas of concern, provide CDS, assess and recommend treatment strategies, analyze outcomes and adverse effects for large cohorts of patients, capture data on uncommon diseases or conditions, and provide data from underserved populations in such efforts. However, differences in EHR encoding systems and data fragmentation across practices and institutions constitute barriers to analyzing these data. The potential uses of EHR data will only be realized with the accrual of data from diverse populations using standardized categories. Networks such as the Electronic Medical Records and Genomics (eMERGE) network have begun addressing these challenges, and their approaches may prove useful in the context of addressing disparities.³¹

Collecting and standardizing data is a complex process.³² One recent report outlines three system-level steps (count electronically, equity lens, and intervene to decrease disparities) needed to decrease racial/ethnic disparities via EHRs and health IT.³³ Routine collection of accurate, detailed, and complete data on social determinants of health, industry/occupation and environment, and demographic and socio-economic status per national guidelines is

needed.^{32,34} The broad adoption of EHRs provides an opportunity to incorporate information on demographic and social determinants of health on a large scale, but terminology and messaging standardization is necessary to enable this.³⁵ Accordingly, the Institute of Medicine identified social determinants of health domains and measures to inform recommendations for the meaningful use of EHRs.³⁶ However, there are differences between EHR systems in large, well-resourced clinical practices and those in less well-resourced sites, such as their relative abilities to support population health management and track, document, and address disparities across settings.³⁷ NIMHD is now working with other NIH institutes and centers to identify common health equity data elements in EHRs and other data sources to make it possible to translate data into actions to improve health outcomes for disparity populations.

While health IT has traditionally focused on the EHR, personal and mobile technologies, such as the smartphone and wearables, are increasingly affecting health care. In 2017, 17 percent of American adults used smartwatches or wrist-worn fitness bands³⁸ that can sense heart rate, physical activity, and even atrial fibrillation (<https://support.apple.com/en-us/HT208955>). App-based interventions, called digital therapeutics, are treating insomnia, depression, diabetes, and many other conditions. Mobile health (mHealth) technologies could reduce disparities by providing relatively inexpensive, large-scale digital interventions to underserved populations. However, adoption rates of such IT is lower in lower-income, rural, elderly, and populations with disabilities.^{39–42} Moreover, current mHealth technologies are available almost exclusively in English, and require high levels of consumer technical literacy to use and maintain. Health systems should guard against exacerbating disparities by ensuring that the mHealth innovations they offer are cross-platform (Apple users average higher socioeconomic status than Android users⁴³), come with sufficient user support, and are multi-lingual. Outreach to diverse populations to collect novel data – such as on sleep, stress, and physical activity – using mHealth technologies should adhere to emerging data standards (e.g., Open mHealth) that are compatible with EHR data standards.

Recommendation #8: Identify deficiencies in the existing health IT system’s ability to support health equity and adopt stakeholder-centered approaches to address these deficiencies.

While the EHR is potentially a major source of actionable data, many practical concerns need to be addressed to ensure its use in this way, such as aligning the needs of healthcare providers and IT engineers; promoting trust in the EHR as a reliable source of data; and making EHRs more user-friendly to clinicians, patients, and researchers. It is also important to examine existing diverse data types, including EHR and non-traditional data sources, to see whether the data produced are biased in a way that may affect or limit our understanding of, or ability to intervene in, disparities reduction. A focus on health disparities is needed at the beginning of health IT planning and implementation.²

Notably, limited interoperability between data bases (exacerbated by vendor data lock) results in a decreased ability to create longitudinal health records. Any effective system-level strategy must also ensure that data is protected. This should include protection from data manipulation, falsification, theft, destruction due to equipment failures or natural and

manmade disasters, and cyber attacks. Researchers should identify and address deficiencies in health IT data exchange systems that may contribute to disparities, especially deficiencies related to privacy and security. Meanwhile, the impact of technological advances in data sharing, including cloud-based technologies, blockchain-based healthcare technologies, and distributed ledger technologies, must be assessed for potential negative impacts on disparities. A stakeholder-centered approach is warranted to address barriers to the ability of IT systems to enhance equity.⁴⁴

Conclusions

This workshop highlights the promises of leveraging health IT to improve health outcomes in underserved populations and reduce health disparities. Ultimately, the goal of health IT research is to improve quality of life for the largest possible number of people. This goal should guide what, how, and by whom standardized data are collected and what interventions are adopted. Open and continuous communication and shared decision-making between clinicians and patients through a health IT system is desirable. For health IT research to address health disparities, standardized data collection enabling aggregation and analysis will be necessary. Data on income, education level, country of origin, and SDH may then be linked to predict healthcare needs and outcomes. Meeting people where they live will optimize health IT's benefits and ensure that disadvantaged patients benefit from these advances. Finally, given the vast ecosystem of (often incompatible) health IT systems supported by different commercial vendors, further research is needed to improve interoperability, data integration, and health information exchange, particularly in under-resourced healthcare settings, such as community health centers, rural health centers, and small private practices. Taken together, the recommendations emerging from this workshop will help move the health IT research field forward to ensure population health equity.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgement:

These summarized findings are based on scientific talks and discussions presented at the NIMHD-funded workshop "Addressing Health Disparities through the Utilization of Health Information Technology," in Gaithersburg, Maryland. The workshop was a collaboration between the National Science Foundation and the National Health IT Collaborative for the Underserved. The authors are grateful to all the speakers, discussants, and attendees of the workshop. Especially, we thank Urmimala Sarkar, MD, MPH and Diane L. Adams, MD, MPH for their critical comments.

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Table 1.

Conclusions from the workshop: “Addressing Health Disparities through the Utilization of Health Information Technology”

Recommendation #1. Promote health IT research that addresses the scalability and sustainability of interventions to improve health equity.
Recommendation #2. Adopt rapid-cycle, continuous evaluation and implementation of new developments in health IT to address social determinants of health.
Recommendation #3. Explore public-private and other partnerships to incentivize the creation and adoption of health IT to reduce health disparities.
Recommendation 4: Improve coordination between IT users and IT developers; increase health IT training in primary care settings.
Recommendation 5: Encourage mixed-methods and participatory approaches to evaluating which health information is most relevant to clinicians and patients to improve health care decision-making.
Recommendation 6: Identify practices, procedures, and programs that promote respect, trust, and equity in the design and implementation of data systems.
Recommendation #7: Standardize data collection in electronic health records and develop innovative technologies to capture new data streams to collect information on health disparities populations.
Recommendation #8: Identify deficiencies in the existing health IT system’s ability to support health equity and adopt stakeholder-centered approaches to address these deficiencies.