

# **Health information technology** and equity: Applying history's lessons to tomorrow's innovations

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Health and health care disparities are widespread with major impacts on outcomes for children and families. Inequitable care is poor quality care. Though health IT has the potential to improve disparities, health IT implementation can have unintended consequences of widening, maintaining, or creating disparities by disproportionately benefiting advantaged children, adolescents, and their caregivers. Narrowing disparities can be achieved by embracing an approach that places marginalized patients at the center of health IT design and implementation. Health care systems can leverage the disparityreducing potential of health information technologies by housing innovation within an equity framework. Initial steps include evaluating for disparities exacerbated by health IT, implementing universal precautions to prevent health IT intervention-generated inequalities, and co-designing future innovations with marginalized communities. By directly addressing community needs, health IT systems designed to effectively benefit underserved children, adolescents, and their caregivers have the potential to yield more equitable health care IT, and better outcomes for our young patients.

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# **Defining health equity**

he Robert Wood Johnson Foundation (RWJF) defines health equity as "everyone [having] a fair and just opportunity to be as healthy as possible." As compared to "equality," equity means that people get what they need and not just whatever everyone else is getting. Accordingly, RWJF goes on to state that achieving health equity requires "removing obstacles to health." obstacles to health can often be grounded in the complex systems inherent to health care delivery – e.g., complicated scheduling systems, convoluted phone trees, insurance barriers, etc. Many barriers outside health care often drive health disparities, i.e., "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population groups, and communities."<sup>2</sup>

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# Health information technology and social determinants of health

One of the most profound changes in the past decade has been the widespread proliferation of health information and communications technologies (HICT). These technologies include those used by health care systems, e.g. electronic health records (EHR) and health information exchanges (HIE) - and by patients and their families, e.g. patient portals and remote patient monitoring software. To understand how health information technologies (health IT) may create or exacerbate disparities, it is imperative to understand that health care disparities are driven primarily by social disparities through upstream and downstream factors.<sup>3</sup> Upstream factors are social determinants of health (SDOH) - the circumstances in which humans live, work, and play – that impact 80% of health outcomes.<sup>4,5</sup> Downstream factors are those closer to an individual patient that exist within the patient's health care system. Writer and social activist James Baldwin once wrote that "people are trapped in history, and history is trapped in them." This insight speaks to the historical sociocultural influences that manifest in countless ways as determinants of health.

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The impact of historical influences extends to the technologies that people create. Digital health innovation, in particular, relies on access to systems and technologies that have demonstrated disparities in availability and, therefore, increased risk of undermining health equity. For example, accessing one's own electronic health records requires more than just a patient portal activation code and consent. Among other things, this process typically requires fast internet speeds; access to a smartphone or home computer; ability to read English; and adequate memory and data on a personal device. If a patient has surpassed their monthly data allotment or receives a sign-up link in English but is prefers a language other than English for healthcare, they may never receive the activation code that was sent or may not be able to read the message even if it is received. Thus, they may never sign

up for the patient portal that helps to remind them of their preventive care visits and miss out on the care and services they would receive at that visit. This example illustrates how disparities in technology availability drive inequity in adoption and usage, which affects the distribution of the downstream benefits of using those technologies to advance health care.

Everyone in healing professions (e.g., clinicians, administrators, clinical staff, information technology, digital health, and innovation laboratories) is account-

able to consider both upstream and downstream SDOH factors in the use and design of health IT.

# Unintended consequences of health information technologies

Technology continues to advance at a blistering pace. A smartphone in 2019 had "over 100,000 times the processing

power of the computer that landed man on the moon 50 years ago." Every day, humans can perform more impressive technological feats. Almost daily

technological breakthroughs affect — and hopefully augment — the capacity to provide high quality health care. However, it is important to carefully consider the unintended consequences that can occur when new health IT is introduced without considering how the innovation will meet the needs of marginalized communities or what human resources and workplace infrastructure is needed to support the new technology. <sup>9,10</sup>

A useful parallel for this approach can be borrowed from quality improvement (QI) methodology, that encourages consideration of "balancing measures." Balancing measures assess whether changes designed to improve one part of the system are causing problems in other parts of the system. Researchers have raised awareness that QI interventions often used to make local, iterative systems changes may inadver-

tently maintain, worsen, or in some cases, create disparities. 12 This could happen because the intervention may improve quality at the same rate for all groups (disparities maintained), at lower rates for disadvantaged groups, or at higher rates for more advantaged groups (disparities widened in either case).

Despite good intentions,

health IT solutions have an even more pernicious possibility of introducing new disparities where none previously existed <sup>13</sup> (Figure 1).

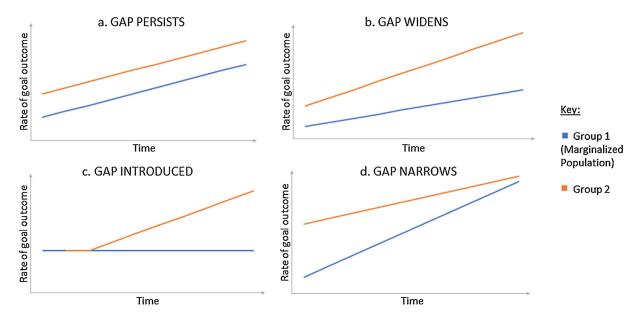
Consider disparities between private and publicly

insured patients for annual preventive care. 14 If an intervention is created to send out a patient portal message to all families to schedule a wellness visit, the patients who have access to portals, technology, and time will be disproportionately advantaged. As a result, the already privileged group might have even more visits compared to the less privileged one. This effect of "intervention-generated inequalities" (IGI) is demonstrated in smoking cessation

interventions, 'Back to Sleep' campaigns, and bicycle helmet legislation.<sup>15</sup> All these interventions had the greatest effect among more affluent populations and

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**Fig. 1.** Effects of Interventions on Disparities. Adapted from citation.

resulted in worsened inequalities than before the intervention.

Equitable care is one of the six domains of health-care quality as determined by the Institute of Medicine. Therefore, inequitable care is poor quality care. As the EHR is increasingly being used to implement quality improvement interventions and aid in clinical decision making, "intervention generated inequalities" may create the most disparities. <sup>17</sup>

# The digital divide

The idea of technology-based interventions being risks for creating or exacerbating disparities is not new. As new technology flourished in the 1990s, the term "Digital Divide" arose to describe a gap between those who had access to the Internet and computers and those who did not. 18-22 A 1995 U.S. Department of Commerce report revealed widespread inequalities of Internet access among marginalized subgroups. (e.g., migrant or ethnic minority groups, senior citizens, those affected by poverty, people living in rural areas, or individuals with lower education.)<sup>23</sup> In the following decade, data from the monthly Census Bureau's Current Population Surveys revealed increasing computer, smart phone technology, and Internet access and use. A federal report in 2004 essentially declared the problem solved. 24 While it is accurate that Internet usage has reached near-saturation levels in most populations, when demographic

groups who have been marginalized by society are considered, the data reveal another perspective.

For example, the American Community Survey (ACS), which examines trends in computer and internet use, revealed that 92% of all households have at least one type of computer and 85% had a broadband internet subscription in 2018.<sup>25</sup> However, disparities become obvious when stratified by SDOH factors: lower rates of internet subscription were associated with a household who rented rather than owned a home and households with limited English-speaking ability. In addition, broadband access and technological device use were lower among racial and ethnic minorities and groups with lower household income, lower education, English as a second language, and disabilities. A 2021 Pew Research Center survey reported that about a quarter of adults with household incomes below \$30,000 a year (24%) do not own a smart phone; about four-inten adults with lower incomes do not have home broadband services (43%) or a desktop or laptop computer (41%).<sup>26</sup> The survey showed that most Americans with low incomes are not computer or tablet owners but that each of these technologies is nearly ubiquitous among adults in households earning \$100,000 or more a year. For pediatrics, the disparities are stark - an estimated 17 million U.S. school children lack internet access.<sup>27</sup>

A dominant 21<sup>st</sup> century idea is that early adopters of new technological advances are inevitably wealthier but that eventually, the innovations trickle down to the masses.<sup>28</sup> Those who oppose this idea argue that

latecomers to technology are persistently disadvantaged, leaving them behind the economic, health, and social benefits of the digital age.<sup>29</sup> Advocates in the field of education argue that equity can be advanced through innovation and deem this technology "Disruptive Innovation".<sup>30</sup> Disruptive Innovations are those that make life-improving technologies more accessible, affordable, and customizable. Disruptive innovation advocates argue that "to ensure that the arc of innovation bends toward equity, all of us whose actions and choices influence innovation need to be ever mindful of whether we are steering innovations toward equity, or maintaining the status quo."<sup>30</sup>

# **Health Care and Digital Disparities**

While data on device and internet disparities were emerging, the U.S. health care system began the first phases of modernization in transitioning from paper to electronic health information systems. In 2009, the Health Information Technology for Economic and Clinical Health Act (HITECH Act) was passed to promote and expand the adoption of health information technology. To meet federal Meaningful Use certification criteria, U.S. health care institutions needed to implement not only electronic health records but also portals by which patients could access their own health record. 31 Starting the same year that initial government incentives were rolled out, research began to document the potential for health information technologies to accentuate disparities.<sup>32</sup> Their concerns were that the same disparities found in the technological foundation of the '90s would be inadvertently introduced into health information technologies.

Equity advocates conceptualize the effects of health IT on health disparities by considering the different experiences of three target user groups — clinicians (via the electronic health record [EHR]); patients and their caregivers (via patient portals, web-based and social-media technologies), or a combination of both (e.g., through remote monitoring devices, pre-visit questionnaires, web-based, patient-entered data, and patient-reported outcomes). The following sections describe how health IT experiences could impact disparities for these different user groups.

## Health IT disparities and use by patients

For health IT used by patients, early concerns of widening the digital divide have proven to be justified.

Early studies found disparities in patient portal enrollment and use, noting differences in access to information about the portal as well as the perceived benefit of the portal. 33 A 2011 study among a disadvantaged patient population showed the odds of receiving an access code were significantly higher for whites, women, younger patients, English speakers, and the insured.<sup>34</sup> Racial disparities were small but persisted when controlled for language, insurance, and health status. A 2013 study in primary care pediatrics demonstrated that significant disparities existed between ethnic groups and insurance types.<sup>35</sup> Medicaid recipients were about one third as likely to enroll in the patient portal and were half as likely to activate it once enrolled. Guardians of children with Hispanic ethnicity and those of Asian and "other" race had decreased odds of enrollment in the patient portal compared to non-Hispanics and whites. Since those early years, numerous studies have shown that despite rapidly increasing patient portal adoption, sociodemographic disparities in portal enrollment, account activation, and utilization persist. 36–40 A decade later, the alarm continues to sound as studies into 2021 continue to document disparities in patient portal use across age, race/ethnicity, and socioeconomic status. 41

Apart from patient portals, other types of health IT such as remote patient monitoring devices for diabetes management have shown similar socioeconomic disparities. 42 A January 2021 study analyzed outcomes patients with Type 2 Diabetes (T2D) who were recently discharged from the hospital.<sup>43</sup> Patients measured their blood glucose, blood pressure, and weight from home, uploading this data to a virtual platform. The study showed that the program decreased the absolute gap in Hemoglobin A1c (HbA1c) reduction between Black and white T2D patients. However, relative to white patients, Black patients uploaded their data less frequently and at program completion had an average HbA1c 0.23 points higher than white patients (p<0.01) and the adjusted odds of Black patients hav- $\frac{1}{1}$  ing HbA1c > 9% was 1.68 times that of white patients (95% confidence interval [1.07–2.63]). The study concluded that higher levels of patient activation and engagement with the program were associated with a lower Hemoglobin A1c at program completion.

Recently, disparities in providing health care through virtual platforms have been amplified by the COVID-19 pandemic. Numerous studies have documented socioeconomic, language, and racial/ethnic disparities in access to and utilization of video visits.<sup>44</sup>

For example, Californian patients with emerging english proficiency had lower rates of telehealth use (4.8% versus 12.3%) compared with proficient English speakers.<sup>45</sup> When analyzing different telemedicine modalities in a pediatric neurology clinic, disparities were also demonstrated between audioonly (telephone) and video visit encounter types. Patients who self-identified as Black comprised 21% of telephone encounters versus 11% of all video visits. Hispanic/Latinx patients made up 14% of telephone encounters compared to 9% of video visit encounters. 46 For people with disabilities, who prefer a non-English language, or who do not have access to internet, both scheduling and accessing COVID-19 vaccine appointments can be a struggle, in part because of the technologies involved.<sup>47</sup>

While Health IT tools for patients may reduce disparities, these examples demonstrate the potential for digital health tools to perpetuate, exacerbate and, even worse, create new disparities. The irony of the effects of the Digital Divide is that it undermines health information and communication technologies that are intended to *improve* access to health care.

## Health IT disparities and use by clinicians

The mechanisms by which health IT for clinicians can inadvertently widen disparities are nuanced. Reducing health disparities, engaging patients and families, and improving population and public health are pillars on which the concept of meaningful use of the EHR rests. 48-51 The core functionalities of an EHR were intended to enable health care systems to be safe, effective, patient-centered, timely, efficient, and equitable, as delineated a decade prior by the National Academy of Medicine (formerly Institute of Medicine).<sup>52</sup> Studies to-date have shown mixed results on the value of the EHR to advance the quality of medical care, with moderate achievements seen primarily in the area of safety. <sup>76</sup> Even less attention has been placed on analyzing the capabilities of EHR-mediated interventions to advance the "forgotten domain" of equity. 53

An area of research that has demonstrated the unintended consequences of EHR-mediated interventions is examination of machine learning algorithms. Machine-learning algorithms use statistics to find patterns in massive amounts of data and make predictions about individual patients.<sup>54</sup> This technology is often employed in appointment scheduling to identify patients with the greatest risk of missing an encounter

(i.e. no show). Studies have shown that when these data are used to place high risk for no show patients into overbooked slots, clinic performance is improved. However, this efficiency comes at the cost of disproportionately overbooking patients from the same demographic group, usually from lower socioeconomic status. 55–57 In addition, the contributing variables to the algorithm often are not visible to the scheduler. Well-intentioned clinic personnel may not realize they are overbooking a patient primarily because the patient is obese, publicly insured, or from a race or ethnic minority group.

# Universal precautions to prevent digital health inequities

Despite good intentions, health IT interventions can unintentionally create, perpetuate, or exacerbate disparities by disproportionately benefiting more advantaged people. This section provides an overview of recommendations to prevent intervention-generating inequalities accentuated by health IT. These recommendations address the important question "What would health information technologies and services look like if we placed the experiences and needs of marginalized groups at the center of their design and implementation?" A summary of the recommendations is provided at the end of the section in the format of Do's and Don'ts to prevent digital health inequities (Table 1).

It is critically important to note that the Digital Divide is more than just access to devices and highspeed internet. 59,60 Even without device or internet barriers, disparities persist in who can use and benefit from digital health tools and increasing onus is being placed on health care institutions and software companies to address these aspects of the Digital Divide. A growing body of recommendations call for reducing the complexity of user interfaces, giving actionable information via simple navigation, and designating human tech support staff to provide technical support. 44,61-63 Investigators have raised awareness that health IT tools are often designed for tech-savvy users, thus creating requirements that the end-user have a high degree of digital literacy.<sup>64</sup> An example of equitable health IT design would be to ensure patients are able to join a telehealth video visit with the fewest steps or clicks necessary. If navigating a mobile app or online webpages is deemed necessary,

#### Dο

- Stratify by Race/Ethnicity, Language, and proxies for Socioeconomic Status (insurance, education, income)
- Use stratification and equity impact assessment tools to identify the baseline disparity gap before beginning any policy, program, or intervention
- Co-design the health IT tool in collaboration with marginalized communities
- Leverage user-centered design to present actionable information with simple navigation for diverse patient backgrounds
- · Track the change in the disparity gap
- Have a mitigation plan to evaluate whether disparities are being created, maintained, or worsened
- Prioritize resources for health-IT mediated interventions tailored for underserved populations
- Leverage EHR-mediated tools (order sets, machine learning, documentation templates) to minimize bias
- Ensure that marginalized populations' needs are requirements for product selection (vision and hearing impairments)

#### Don't

- Use white patient populations as the sole comparison group
- Overlook the need for supportive intermediaries such as digital health navigators or patient-facing technical support phone numhers
- Design patient- or clinician-facing health IT interventions without also developing the workplace infrastructure to support marginalized communities use of health IT
- Conduct end-user testing of health IT interventions solely with English-speaking, tech savvy users
- Limit evaluation of user-experiences through single platforms (mobile vs computer, Apple vs Android, high vs low internet speeds)

these should provide only the information needed to participate in the video visit and in the patient's preferred language. For patients and families with physical disabilities, health IT tools may widen disparities if there are no capabilities for closed captioning, sign language interpretation, or audio guided accessibility. To overcome these barriers, co-design of the health IT tool in collaboration with marginalized communities will quickly raise awareness regarding the needs of the community. This extends to ensuring that end-user testing of health IT interventions is not done solely with English-speaking, tech-savvy users.

# Data and Health Equity

To ensure disparities are not being exacerbated by health IT interventions, the collection of accurate data is vital for ongoing monitoring and evaluation. It should be noted that there is no consensus on exactly which metrics are best suited to reveal health and healthcare disparities. However, there is broad agreement that demographic stratification—that is, the breaking down of a single metric based on specific demographic categories—is a reasonable first step. 12 The purpose of demographic stratification is to uncover potential disparities, not to establish a causal relationship between demographic characteristics and clinical processes/outcomes. As a starting point, measures of interest should be stratified by patient's race, ethnicity, and language, a set of characteristics referred to as REaL data. 12 However, white patient populations should not be used as the sole comparison

group. Data should also be stratified by additional variables, such as insurance type (e.g., Medicaid vs commercial) which may be a proxy for socioeconomic status (SES), and publically available census data such as the Center for Disease Control's Social Vulnerability Index. These variables add additional context to REaL stratified analysis and can be used to guide cohort identification for interventions.

Data that are unavailable because they are not documented in a culturally appropriate manner impairs equity-framed health IT interventions. For example, language preference documentation should be documented for caregivers of a child or adolescent as well as for the child or adolescent, to ensure adequate provision of language services. Nevertheless, this should not hamper efforts to evaluate such data, as disparities may still become evident. Conversely, a lack of data to prove a disparity gap must be taken in context of data quality. Inevitably, questions emerge regarding data validity and completeness and can be leveraged to drive further improvement initiatives. Beyond REaL data, new health-IT mediated approaches are needed to confidentially and effectively identify, document, and meet social needs such as transportation, housing, and food insecurity.

# Leveraging health information technologies to close disparity gaps

When interventions disproportionately benefit the underserved group, then disparities are successfully

reduced. Co-designing digital health solutions with underserved communities and historically marginalized populations is a key component to this success. Dr. William Osler, offers simple yet profound guidance: "listen to the patient." Patient-centeredness means ensuring "specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements."

Innovation in the following examples demonstrate how to leverage health IT as an equity-promoting tool. A team that exemplified collaborative, equity-focused QI was a hypertension collaborative in Upstate New York. 68 The team engaged underserved communities in designing interventions to

Health care systems can leverage the disparity-reducing potential of health information technologies by housing innovation within an equity framework.

improve hypertension control and reduce disparities. The initiative used data in 13 different EHRs and resulted in improvements in blood pressure control and reductions in some targeted disparities. In Philadelphia, an emergency room team assessed racial differences in sepsis recognition using an EHR sepsis alert system.<sup>69</sup> Non-Hispanic white patients were more likely than Non-Hispanic Black patients to be treated for sepsis when the alert system was not utilized, suggesting the impact of the EHR on overcoming implicit bias when using clinician judgment alone. A low-tech solution - text messaging- was used in a remote monitoring program to reduce racial disparities in postpartum blood pressure ascertainment.<sup>70</sup> Early in the COVID-19 pandemic, an equity-focused team at the authors' academic medical center helped redesign the pathway that providers used to assess who should be tested for COVID-19. Social determinants of health were added to the criteria to prevent perpetuating the under-testing of the marginalized populations who often serve as essential workers. A program in Chicago used a community participatory co-design approach to address disparities between Black and white patients in receiving time sensitive stroke preventing medication—tissue plasminogen activator (tPA). 71 The program identified that the significant delay in Emergency Room arrival for Black compared to white patients impacted whether tPA could be administered. The interventions included addressing community-identified factors that impacted EMS activation such as bias and fear of discrimination associated with some of the local hospitals and financial considerations such as patients' concerns for ambulance charges and lack of health insurance. In one final example, LifeBridge Health, a health service provider in the Greater Baltimore, Maryland region, used a state-developed COVID-19 Vulnerability Index to proactively identify and contact residents in West Baltimore neighborhoods who were at highest

risk of severe COVID-19 complications. 72

Health IT can be an effective tool in advancing health equity if interventions are thoughtfully and intentionally designed to minimize bias and the effects of social determinants of health. Examples of opportunities to leverage health IT to close disparity gaps include using

missed appointment (i.e., no show) risk scores to coordinate outreach efforts for patients with multiple missed encounters, putting processes in place to provide multilingual patient portal access, and utilizing population health registries to strategically reach patients from marginalized communities overdue for vaccinations. With equity as the goal and children and adolescents' well-being as the compass, medical practices can successfully navigate the challenges noted in this paper.

# Call to Action: Where should we go from here?

Health information and communication technologies are a critical part of the health care infrastructure and are here to stay From the authors' perspective.

Health care systems can leverage the disparityreducing potential of health information technologies by housing innovation within an equity framework.

Health care practices, systems, and individuals seeking to provide equitable care and to minimize the effects of bias can implement the following guidelines.

## For medical practices and hospital systems: Commit to advancing health equity through health IT

Everyone committed to quality care has a responsibility to promote equitable care. Inevitably,

practice settings large and small will be pulled in different directions by competing obligations. Advocates for this work will run into resistance - "we don't have the time or resources to include minority groups into the decision making or design of the digital health tools our clinic uses;" or "We will innovate and refine the new health IT tool for the majority populations first, then make it available for minority populations;" or any of the other myriad excuses and explanations as to why the marginalized must remain marginalized.

Necessity as the mother of invention is a useful concept for health equity and innovation. Just as wheel chair access mandates catalyzed the invention of sidewalk ramps, similarly, medical practices and hospitals can design innovative solutions for equitable health IT when all are agreed upon the absolute necessity to prioritize underserved communities. Championing equitable health IT innovation does not inherently discourage use of the patient portal or other emerging digital health tools. High-tech resources may be used to reach certain populations efficiently and effectively, with concomitant investment in and prioritization of low-tech, high-touch resources to reach other populations efficiently and effectively. For example, the patient portal may be used to schedule COVID-19 vaccines with little effort. At the same time, multi-lingual text-based and phone call outreach can be developed for patients who do not have an active portal account or whose preferred language is not English, live in high social vulnerability neighborhoods, or are publicly insured.

### Kotter's 8-Step Change Model



**Fig. 2.** Kotter's 8-Step Change Model. Adapted from "Leading Change", by John P. Kotter, 2012.

# Individuals in the healing professions: Advance health equity through quality improvement

It can be daunting to tackle complex problems. However, as Reverend Doctor Martin Luther King, Jr. once said, "You don't have to see the whole staircase, just take the first step." A healthy appreciation of the intricacies of social factors, policies, and the dynamics of change management need not preclude action but should inform it. Aim for progress over perfection. Equity-focused work is often challenging, not least of which because of institutional challenges. Clinician's may initiate change following Kotter's 8-Step Model (Figure 2). The first step is to help others see the need for change through a bold, aspirational opportunity statement that communicates the importance of acting immediately.

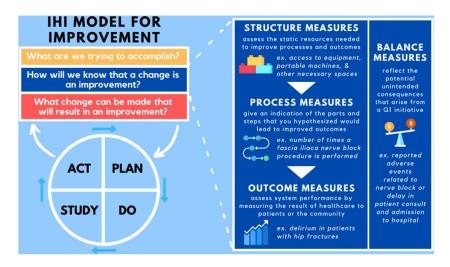


Fig. 3. Institute for Healthcare Improvement's Model for Improvement and Associated QI Measures. Creative Commons BY-NC-SA 4.0 license. Copyright: CanadiEM, 2020.

QI provides a structured approach to effectively create small changes that can build on themselves over time. The Institute for Healthcare Improvement has copious resources to help develop QI skills using their Model for Improvement (Figure 3).75 Health equity experts lay out a model for using quality improvement science in Pediatrics specifically to address health disparities, calling on us to "consider the evidence for particular interventions and the context in which they were developed, directly engage the social determinants of health, and leverage community resources to build collaborative networks and engage community members."12 There are also national resources such as the American Academy of Pediatrics Section on Minority Health, Equity, & Inclusion. It is a rich community with clinicians from diverse backgrounds and practice settings who all have one thing in common - a passion for health equity. Members active in the local American Academy of Pediatrics chapter can be a voice for implementing needed policies. Additionally, members could start exploring local community partners who may help address community-identified needs once social needs identification is confidentially and effectively routine in the practice. Intentionality is key, and that intention starts with making health equity a priority.

# Conclusion

Health and health care disparities are widespread with major impacts on outcomes for children and families. Though health IT has the potential to improve disparities, health IT implementation can have unintended consequences of widening, maintaining, or creating disparities by disproportionately benefiting advantaged children, adolescents, and their caregivers. Narrowing disparities can be achieved by embracing an approach that places marginalized patients at the center of health IT design and implementation. Initial steps should include working with marginalized families, continuously monitoring the change in gap in over time. By directly addressing a known need, designing health IT systems that effectively benefit underserved children, adolescents, and their caregivers has the potential to yield more equitable health care IT, and better outcomes for our young patients.

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