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Perspective

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Good intentions are not enough: how informatics interventions can worsen inequality

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ABSTRACT

Health informatics interventions are designed to help people avoid, recover from, or cope with disease and disability, or to improve the quality and safety of healthcare. Unfortunately, they pose a risk of producing intervention-generated inequalities (IGI) by disproportionately benefiting more advantaged people. In this perspective paper, we discuss characteristics of health-related interventions known to produce IGI, explain why health informatics interventions are particularly vulnerable to this phenomenon, and describe safeguards that can be implemented to improve health equity. We provide examples in which health informatics interventions produced inequality because they were more accessible to, heavily used by, adhered to, or effective for those from socioeconomically advantaged groups. We provide a brief outline of precautions that intervention developers and implementers can take to guard against creating or worsening inequality through health informatics. We conclude by discussing evaluation approaches that will ensure that IGIs are recognized and studied.

Key words: health equity, consumer health informatics, population health informatics, social determinants of health, evaluation, unintended consequences

INTRODUCTION

Health is marked by pervasive inequalities known as health disparities. Disparities arise when disease incidence, prevalence, morbidity, mortality, or survival is worse in a population subgroup than in the general population.[1,2] Health disparities are thought to emerge from health system disparities[3] and socioeconomic factors that create differential access to "flexible resources" including money, status, power, freedom, knowledge, and social capital.[4,5] Such flexible resources can be used to reduce negative health exposures and adopt health-enhancing behaviors.[4,5] Differential resource access is linked to social conditions such as: inequity in education, occupational prestige, and income[5,6]; residential segregation[7]; environmental barriers[8,9]; stigmatization[10]; and discrimination.[7,11] Accordingly, our health and healthcare are strongly influenced by our race and ethnicity, our socioeconomic status (SES), our age, our gender, where we live, and whom we love. Health equity is important on ethical grounds, and because disparities produce negative social and economic consequences at a national scale.[12]

Those of us in health informatics aspire to improve well-being, to alleviate suffering, and to make healthcare better and safer. Because we have such benevolent goals, we often think the worst thing that could happen is for our efforts to have no effect. However, there is a real and more pernicious possibility: that our technological interventions do work, but they work better for those who are already better off. When this happens, our work actually *increases* inequality. This phenomenon, unfortunately well established in public health, is known as "intervention-generated inequality" (IGI).[13,14]

Some of the great public health success stories of the last 50 years have been marked by IGIs. For example, during the period when the tobacco smoking rate in the US population dramatically declined, inequality in smoking rates rose sharply. It is undoubtedly positive that the adult smoking rate has dropped from 47% in 1953 to 15% today.[15,16] Yet in 1953, smoking rates were similar at all education levels,[15] while today, fewer than 4% of graduate-degree holders smoke compared to 34% among adults with a high school-level education.[16] While this does represent significant improvements in smoking rates for lower-SES people, their gains were of a much smaller magnitude than those of their more educated counterparts. Among the reasons is that some anti-smoking interventions are less effective for people with lower education levels.[17–19] If we had a chance to revisit 20th-century anti-smoking initiatives with today's knowledge, we might instead seek policies that provided the biggest benefits to those with the least education. Benefiting this group is likely to be a good allocation of limited public resources because low-SES groups typically carry the heaviest burden of disease.

In this perspective article, we propose that health informatics interventions pose a particular risk of producing IGI because they are likely to disproportionately benefit more advantaged people. We discuss characteristics of interventions known to produce IGI, explain why informatics interventions are vulnerable to this phenomenon, and describe some precautions we can take to improve health equity through informatics.

HOW DO HEALTH-RELATED INTERVENTIONS GENERATE INEQUALITY?

An intervention produces inequality if it is (a) more accessible to, (b) adopted more frequently by, (c) adhered to more closely by, or (d) more effective in socioeconomically advantaged groups such as those with more resources or education[13,14] (Figure 1). Because disadvantaged social status is strongly associated with worse health status,[1] the intervention can leave behind the people most in need of health-related assistance. Even in cases where interventions produce an average improvement because of beneficial effects on many individuals, they can still worsen disparities between the most and least advantaged.

Access

Inequitable access occurs when interventions are made available through channels not equally available to all. The information technologies through which we deliver informatics interventions are disproportionately available to well-off, educated, young, and urban patients[20–23] and to urban and academic medical centers.[24] Computers, smartphones, and commercial health-tracking devices are used more often by people with higher incomes and education (for example, 95% of Americans earning at least $100 000 have smartphones, compared to only 64% of those earning $30 000 or less).[25,26] Access to broadband Internet cannot be assumed or may be more expensive in rural settings,[5,27] and lack of neighborhood broadband has been associated with non-adoption of patient portals.[28] Low-income and racial minority groups may have Internet access only on mobile devices,[27] and many disadvantaged groups, including seniors, may use cell phones rather than smartphones.[27,29] In the Global South (the developing nations of Africa, Latin America, and Asia), 2G wireless remains a key infrastructure for access to the Internet.[30,31]

Other intervention delivery channels that are disproportionately available to the better off include corporate wellness programs (available only to the employed[32,33]) and even medical centers (available disproportionately to the insured).[34]

Bias is another potential source of inequitable access. When we delved into socioeconomic disparities among patient portal users, we found that minorities and uninsured patients were less likely to get portal accounts set up by their clinicians.[35] Although clinicians may have been merely trying to select patients likely to use the portal, the result was unequal access to what was then a novel technology.[35]

Adoption or uptake

Early adopters who first take up innovations tend to have more social and economic resources; only later (if at all) do innovations reach those with fewer resources.[36,37] In health informatics, we see that online mental health and substance use interventions are adopted more frequently by people with higher SES,[38–40] even though these conditions are more prevalent among those with lower SES (eg[41–44]). Patient portal adoption has also been marked by SES disparities, especially in the early years of portals.[35,45]

Poor usability creates a barrier to adoption that is bigger for those with less computer experience.[46,47] For example, less computer-savvy patients required more assistance and succeeded in fewer tasks when using an electronic patient portal.[48,49] Chronic disease patients may need more technical or provider support to use a portal than is typically available.[50]

Distrust in either technology or the medical system can be a barrier to adoption.[51–54] African-Americans are more likely than whites to distrust the medical system and report experiencing racism in it.[55] African-Americans are also more likely express concern about threats to privacy from electronic health records.[56,57] Barriers to adoption also arise when people cannot find experienced friends or acquaintances to help them try or learn to use a new technology, a phenomenon more likely in less affluent social networks.[37,58–60]

Adherence

After trying an innovation, people with less formal education are more likely to drop out of it; this has been found in interventions for mental health,[61,62] smoking,[63–65] pediatric health conditions,[66] alcohol consumption,[67,68] healthy eating, and physical activity.[69–71] The pattern was also found in completion of highly structured online modules,[61,64,72] use of less-structured interventions,[63,66,67,69,71] and completion of assessments in a study.[67,70] Adherence may be higher among more advantaged groups because of usability- and literacy-related demands, along with better access to money, time, and coping skills.[73,74] Also, when people face material stressors such as housing or food insecurity, health maintenance and disease management may have lower priority.[75,76]

Effectiveness

Informatics interventions are sometimes less effective in disadvantaged populations. In some cases, this may be because of reduced efficacy within the population (eg less numerate patients will derive less benefit from quantitative information about health risks than more numerate people will).[77] In other cases, efficacy may be similar but overall effectiveness may be impaired by the other factors noted above: poor access, adoption, or adherence.[78–82] The effectiveness gap is clear in the evidence about information-technology interventions. For example, technology-based physical activity interventions for senior citizens result in less activity among women than men[83,84] and among older seniors than younger ones[85,86]—two groups already less likely to exercise.[87] Many information technology-based interventions targeting diet and obesity are less effective in those with lower SES,[88–91] even though they are already less likely to have a healthy diet[92] and are more likely to be obese.[93,94] Patient education and decision-support interventions that promote patient en-

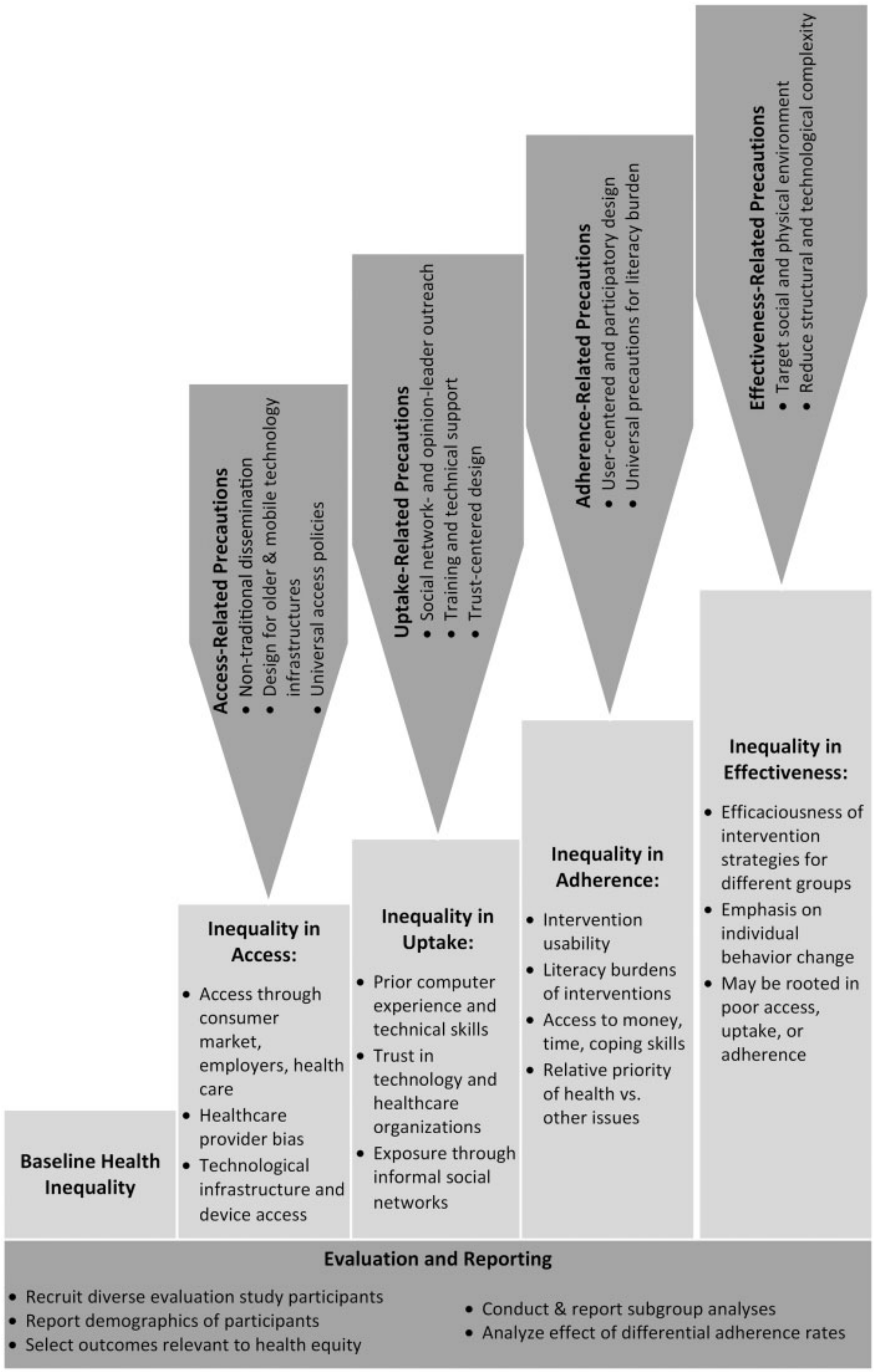

Figure 1. Model for intervention-generated inequality (IGI) prevention.

gagement are frequently less effective in people with lower education, literacy, or health literacy levels,[77,95–100] and these are the populations that are already less likely to be actively involved in their healthcare.[101,102] Overall, interventions focused on individual behavior change are likely to be less effective in disadvantaged populations because barriers to change are greater in these populations. These barriers range from low literacy (impairing comprehension) to limited resources (including longer distances to sources of healthy food or parks for outdoor recreation) to competing priorities (eg lack of time to focus on health priorities while working multiple jobs).[14,103]

WHAT PRECAUTIONS CAN WE TAKE TO AVOID WORSENING INEQUALITY?

The access-adoption-adherence-effectiveness framework can be helpful for health informaticists and researchers seeking to avoid or minimize IGI.

Table 1. Inclusive design decisions and affected groups

Design element	Some affected groups	Example	Relevant literature
Interaction design			
Modes of input	Deaf people, People with cognitive impairments, people with low literacy	Due to literacy challenges, Deaf people may be more able to input information using icon selection and manipulation	118–121
Error handling	People with cognitive impairments, people with low literacy, seniors	People with low literacy make more spelling errors; thus search interfaces should have high error tolerance regarding spelling	118,122
Information architecture	People with Cognitive Impairments, Seniors	Due to memory issues, seniors find it easier to find information within a system with a shallow information hierarchy	123,124
Information design			
Visual presentation of information	Blind people, deaf people, people with low literacy, seniors	Tonal feedback can ensure comprehension of graphs and data visualizations by blind people	115,125–127
Auditory presentation of information	People with cognitive impairments, people with low literacy, seniors	People with low literacy or cognitive impairments may better comprehend textual information accompanied by audio narration	126,128,129
Interface design			
Layout	Blind people, seniors	For seniors, information should be placed in the center of the screen so as to address reduced peripheral vision	130,131
Buttons and icons	People with cognitive impairments, seniors	Older adults may find it easier to tap on larger buttons and icons	132,133
Navigation design	Blind people, people with low literacy, seniors	People with low literacy find it easier to navigate within mobile applications that use linear (versus hierarchical) navigation	131,134,135
Sensory design			
Graphics	Blind people, deaf people	To faciliatate use with a screen reader, alt-text must be provided for all images, including icons and blank images	136,137
Type	People with low vision, seniors	Larger font sizes are more legible for seniors, and people with low vision	121,138
Colors	Blind people, Deaf people	For deaf individuals, color and boldness of text can provide visual intensity that communicates emotional prosody	137
Contrast	Seniors, people with low vision	High-contrast images and text will be more easily perceived by older adults with vision loss	126,139

To achieve equal *access*, we should broaden our channels for dissemination to include nontraditional venues such as libraries, faith-based organizations, and community groups. Because public libraries provide access to the Internet for many without individual access,[104] they are particularly important for reaching low-SES people. We can also keep in mind the need to reach out to less well-off users by developing technologies that use slower Internet speeds and older infrastructures such as short message service.[105] Blended online-offline interventions may also improve access. Patients in disadvantaged groups may be less likely to opt in to innovations, so, as we recently showed with an electronic patient portal, replacing an opt-in approach with a universal access/offer policy can narrow disparities.[106]

To ensure equality in *adoption*, we need to devote resources and time to thoughtful dissemination and implementation strategies for novel technologies. These are likely to include training, social networks, and opinion leader outreach,[107] and substantial technical support for new users.[108] "Trust-centered design" promotes systematic attention to trust in intervention strategy, functionality, and interaction design.[109,110]

Truly user-centered and participatory design can improve *adherence, adoption*, and *effectiveness*. Even when there are insufficient resources for lengthy participatory design processes, we can apply established principles of inclusive design to ensure that innovations are accessible to all (Table 1). We also recommend the "universal precautions" approach to health literacy,[111,112] in which organizations design communications strategies with the assumption that any patient may need literacy support,[113] rather than seeking to identify subsets of low-literacy patients for special attention. Universal-precautions measures include writing actionable content,[114] using plain language, using visuals such as pictographs,[115–117] and minimizing text-based input.[118]

Overall, our goal should be equity in *effectiveness*. Interventions that target "upstream" factors such as the social and physical environment and food access are more likely to be equally effective for advantaged and disadvantaged groups than interventions that target individual behavior.[140,141] Efforts to simplify structural and technological complexity are likely to disproportionately benefit less advantaged groups[142]; one reason for this may be the effort involved in negotiating additional barriers to health behaviors that emerge in high-poverty contexts (eg[143]). One successful complexity-reduction effort was to hyperlink medical terms in a patient portal directly to an online medical encyclopedia, simplifying searches by bypassing the need to use search engines or filter untrustworthy sources.[144] The population who used the hyperlinks reflected the racial diversity

Table 2. Designing and analyzing health informatics evaluations with health equity in mind

- Identify equity-relevant independent variables
- Choose at least one equity-relevant outcome variable
- Recruit diverse participants, and report their sociodemographics in detail
- Ensure sufficient statistical power for subgroup analysis or analysis of effect modifiers
- Plan for qualitative data collection regarding potential unintended consequences, probing for equity-relevant issues

of the patient population, without the racial, ethnic, and socioeconomic disparities found in general Internet health information seekers.[145] Work system-oriented technology design approaches[146,147] could also reduce complexity of patient work in the home and community, with special attention to addressing the manifestatisons of socio-economic constraints where possible.

We also propose that improved evaluation and reporting in the health informatics literature will help achieve more equitable outcomes. Formative and summative evaluation must include more participants from disadvantaged groups, meaning we must be willing to devote additional resources to sampling through interpersonal contacts (cluster or snowball sampling), community organizations,[39,148] maximum variation sampling for qualitative interviews,[149] and quota sampling for surveys.[150] At a minimum, published studies should report relevant sociodemographics of samples. These demographics should include at least some of the so-called PROGRESS-Plus factors of known concern to health equity: place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education, SES, and social capital as well as age, disability, and sexual orientation.[151,152] We also encourage researchers to plan for health-equity focused analyses, including powering their evaluation studies for subgroup analysis or analysis of effect modifiers, while following rigorous standards for heterogeneity of treatment effect (HTE) analyses[153] (Table 2). Intervention researchers should also plan studies that seek to understand unintended consequences; qualitative data collection probing equity issues would be especially suited for this task.

Finally, we also encourage health informatics practitioners and researchers to recognize the larger policies and social issues that create and and exacerbate health inequality. In recognition of the multifaceted nature of the problems we face, health informaticists might consider engaging in broader research on social determinants of health beyond those directly pertinent to information technology, as well as advocating for evidence-based policies that narrow health-related inequality.

CONCLUSION

Many health informatics interventions may not themselves address many of the social factors contributing to health disparities, such as poverty, residential segregation, and discrimination. However, in situations where they have any effect at all, they carry a risk of creating IGI, and thus worsening underlying inequalities. We propose that such IGI can be minimized or prevented through thoughtful decisions about access, uptake, adherence, and effectiveness. IGI can also be detected through careful evaluation design. We encourage health informaticists to recognize the potential that their work has to create IGI, and to consider the precautions outlined here to prevent them. If we address the potential for IGI proactively, we will have a better chance of meeting our collective aspirations to improve health and healthcare—not just for those who already benefit from health-related advantages, but also for those who need us most.

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CONTRIBUTORS

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CONFLICT OF INTEREST

None declared.

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