Good Intentions Are Not Enough: Health Informatics Interventions That Worsen Inequality [Panel]

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Abstract

Health informatics interventions pose a particular risk of producing intervention-generated inequalities by disproportionately benefiting more advantaged people. We discuss characteristics of 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 through attention to equity issues at four phases of the "intervention cycle": efficacy, uptake, service access/provision, and usage/adherence. Key safeguards involve developing interventions that focus on "upstream" factors leading to poor health, and that are at least as effective in health disparities populations as in other groups, and potentially even more effective. Additionally, adoption of equity-aware strategies to facilitate access, uptake, and adherence are critical. We conclude with a discussion of evaluation and measurement approaches that will ensure that IGIs are recognized and studied.

Panel Description

Those of us who have chosen to conduct research in health informatics have typically done so hoping to make a difference in healthcare. We hold aspirations of improve well-being, of improving health care better, and of reducing human suffering due to disease. Many of us also care specifically about reducing health disparities, or well-documented differences the incidence and prevalence of disease, as well as disease-related morbidity, mortality and survival rates in one group when compared to the general population. Because we have such good intentions, we often think the worst thing that could happen is that our efforts would have no effect. However, there is a 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, well established in public health, is known as "intervention-generated inequality" (IGI). Unfortunately, **health informatics interventions pose a particular risk for of producing IGIs by disproportionately benefiting more advantaged people.**

This panel aims to build awareness of the potential for IGIs, and to explore potential strategies for mitigating them. A health informatics intervention can produce inequality if it is (1) more effective among socioeconomically advantaged groups, (2) more accessible to advantaged groups, (3) adopted more frequently by advantaged groups, or (4) adhered to more closely by advantaged groups. Each of these four options represents a stage of the "intervention cycle," times at which time there is a need to guard against the possibility of IGIs. Accordingly, we will organize our panel around each of these phases, as well as reporting.

Overview of Intervention-Generated Inequalities (IGI) (Tiffany Veinot)

Beginning with the motivating example of smoking cessation efforts, the concept of IGIs will be defined. Next, the factors that place HI intervention strategies at risk of producing IGI will be introduced, and their potential emergence at each stage of the intervention cycle illustrated. Differences between population-based and disparity population-focused intervention strategies will also be emphasized.

IGI stemming from differential efficacy (Andrea G. Parker)

The first stage of intervention cycle at which inequalities might emerge is *efficacy*, where an intervention works better for one group than another. For example, people with lower socioeconomic status (SES) are less likely to have a healthy diet (1), and more likely to be obese (2, 3); yet, technology-based interventions targeting these outcomes are more effective in those with higher SES (4-7). An explanation for this is that traditional obesity interventions that are *equity-negative* in low-SES populations focus on "downstream" strategies like the provision of information and nutrition counseling to individuals to facilitate their behavior change (8, 9). In contrast, interventions that are *equity-positive* in low-SES populations focused on "upstream" factors at the structural and environmental level, like making

environmental changes that make healthy eating and exercise easier — such as food pricing policies and transportation to exercise facilities (8, 9). Thus, IGI may be mitigated by emphasizing "upstream" informatics intervention strategies such as: (1) supporting environmental changes via ambient technologies (10); (2) catalyzing community activism concerning health (11, 12); (3) providing health equity-focused, social computing-based surveillance and decision support for elected and administrative decision makers such as urban planners and public health officials (e.g., (13)); (4) expansion of access to resources through coordination and process simplification (e.g., (14)); and (5) developing targeted informatics interventions focused on health disparity populations.

IGI stemming from differential access (Tiffany Veinot)

When interventions are available through the consumer market, healthcare organizations and employers, this will create inequitable access. For instance, commercial health tracking devices are used more by people with higher than lower education levels and incomes (15). Technologies made available through healthcare will also reliably reach more well-off people; even in countries with universal healthcare access such as the UK, low-SES people are less likely to go to the doctor for preventative care (16). Corporate wellness programs may also give away or stimulate use of tracking technologies, which advantages employed people. The information technology platforms through which we deliver interventions also tend to be more accessible to educated, well-off, young, and urban people (17-20). Healthcare provider bias can also emerge when a technology must be offered to a patient, or it use encouraged (21). Consequently, we advocate partnerships with nonprofit organizations and public libraries to provide intervention access, continued design for older technological infrastructures such as SMS, and making linkage to informatics interventions routine, rather than requiring opt-in from providers.

IGI stemming from differential uptake/adoption (Courtney Lyles)

Health interventions for the public are marked by an "inverse equity law," whereby population-focused interventions initially widen social inequalities due to "preferential uptake" by more advantaged groups (22). A key example of this law is patient portals: while patient portals are being widely implemented and may contribute to improved health outcomes, there is evidence that racial/ethnic minorities and patients with limited health literacy, income, and education are less likely to use portals (23-26), despite uniformly high interest in online access to personal health records (27). The differences in portal use cannot be attributed to computer/Internet access alone (25). Potential reasons for nonuse include lack of awareness (27), lack of sufficient computer skills (25), reduced ability to understand medical content or limited health literacy, differential perceptions of the value of portal features (28), poor usability of portal websites/interfaces (29), need for provider or system support (30), and concerns about online security (25). These findings suggest issues to address in patient portal implementation, which can be addressed in part through targeted approaches such as trust-centered design (31) and tailored training programs.

IGI stemming from differential usage/adherence (Katie Siek)

Inequalities might also emerge in how intervention is used, and whether it is used as advised. Numerous studies have shown that people with less formal education are less likely to adhere to informatics interventions; this was present in interventions for mental health (32, 33), smoking (34-36), alcohol consumption (37, 38), healthy eating and physical activity (39-41). Because an inability to use technologies is often a reason given for abandoning technologies (42, 43), we discuss designing usable systems for people with low literacy, who are more likely to have less formal education. We will contrast personal health usage with how people with disabilities abandon technologies designed for their abilities to re-appropriate commodity technologies and modify them for their own purposes. We encourage researchers to use a mix of user centered and participatory design techniques to better design systems for all abilities (44).

Evaluation and Reporting (Jessica Ancker)

When we study informatics interventions, we need to show not only whether the intervention is effective but also whether it improves or worsens equity. We need to design studies that include diverse participant samples, and power them to provide robust estimates of the effect overall and within subgroups of interest. Hence, if we want to show that our intervention is just as effective in low-literacy patients as high-literacy patients, we need to make sure we have included enough low-literacy patients to draw firm conclusions in subgroup analysis. We also advocate enforced reporting regarding the equity impact of interventions by the journals and conferences in which we publish. The first reporting guideline, CONSORT, was developed in the 1990s by a consortium of medical journals to standardize published descriptions of randomized trials; the goal was to ensure that reviewers and readers could assess the validity of the trial. Almost immediately, journals that enforced CONSORT documented an improvement in the quality of randomized trials. If the publication venues we respect required us to report the effect of our interventions on equity, the result would be more transparency about this topic which would lead, in the long run, to beneficial effects.

Panelist Biographies

Tiffany C. Veinot (Moderator/Panelist)
Tiffany C. Veinot, MLS, PhD is an associate professor (with tenure) at the Schools of Information and Public Health and Director of the Master of Health Informatics Program at the University of Michigan. Her primary research interests focus on developing and evaluating "community health informatics" interventions. Community health informatics focuses on the potential of socio-technical interventions to improve the health of marginalized groups and reduce health disparities. She is the Principal Investigator of a 5-year study funded by the Patient-Centered Outcomes Research Institute, "Enhancing the Cardiovascular Safety of Hemodialysis Care: A Cluster-randomized, Comparative Effectiveness Trial of Multimodal Provider Education and Patient Activation Interventions (Dialysafe)." She has also held or co-held grants from the Centers for Disease Control and Prevention, Department of Veterans Affairs, Institute of Museum and Library Services, Canadian Institutes for Health Research, Social Sciences and Humanities Research Council of Canada, Canadian Foundation for AIDS Research and Ontario HIV Treatment Network. Her published research has garnered awards from the American Medical Informatics Association, ACM Special Interest Group on Computer-Human Interaction, Journal of Documentation, Canadian Association of Information Science, the American Society for Information Science & Technology, and the Association for Library and Information Science Education.

Jessica S. Ancker (Panelist)
Jessica S Ancker, MPH, PhD, FACMI, is an associate professor of health informatics at Weill Cornell Medical College. Her main areas of research are electronic patient portals, effect of health information technology on decision-making, and evaluation methods in health informatics. She is the recipient of a K award from the Agency for Healthcare Research and Quality and has received funding from the Patient-Centered Outcomes Research Institute, the National Science Foundation, and the New York State Department of Health. She holds an MPH in biostatistics and a PhD in biomedical informatics, both from Columbia University. Before she went to graduate school, she had a previous career in journalism.

Courtney R. Lyles (Panelist)
Courtney R. Lyles, PhD is an Assistant Professor in the UCSF Division of General Internal Medicine at Zuckerberg San Francisco General Hospital, Associate Faculty Member at the UCSF Center for Vulnerable Populations, and an Affiliate Investigator at the Kaiser Permanente Northern California Division of Research. Dr. Lyles received a PhD in Health Services from the University of Washington. She is currently Principal Investigator of a career development award from the Agency for Healthcare Research and Quality and co-Principal Investigator of a G08 grant from the National Library of Medicine to engage patients in using online patient portals for healthcare management. Dr. Lyles' research focuses on harnessing health information technology to improve patient-provider communication for chronic disease self-management to ultimately reduce disparities in health and healthcare outcomes. Dr. Lyles has led several studies evaluating the impact of health technology on quality and clinical outcomes, as well as conducted extensive work with diverse patients to understand usability needs and preferences in using health technologies, both in clinical settings and in their everyday lives.

Andrea G. Parker (Panelist)
Andrea Grimes Parker is an Assistant Professor at Northeastern University, with joint appointments in the College of Computer & Information Science and the Bouvé College of Health Sciences. She holds a Ph.D. in Human-Centered Computing from Georgia Tech and a B.S. in Computer Science from Northeastern University. Dr. Parker is the director of the Wellness Technology Lab at Northeastern University. This interdisciplinary research group spans the domains of human-computer interaction, personal health informatics, and public health to examine how social and ubiquitous computing systems can help reduce ethnic, racial and socioeconomic health disparities. Much of her research has focused on the design and evaluation of interactive systems that help neighborhoods care for themselves, and systems that encourage adolescent and family-based behavior change. Dr. Parker's research has been funded by the National Science Foundation, the National Institutes of Health, and the Aetna Foundation. She is currently Principal Investigator of an NSF-funded project to examine how smartphone applications can be designed to encourage physical activity in single and multiple-caregiver low-SES households. Dr. Parker served as the National Evaluator for the Aetna Foundation's portfolio of projects on mobile health interventions in community settings.

Katie A. Siek (Panelist)
Katie Siek is an associate professor in Informatics at Indiana University Bloomington. Her primary research interests are in human computer interaction, health informatics, and ubiquitous computing. More specifically, she is interested

in how sociotechnical interventions affect personal health and well-being. Her research is supported by the National Institutes of Health, the Robert Wood Johnson Foundation, and the National Science Foundation including a five-year NSF CAREER award. She has been awarded a CRA-W Borg Early Career Award (2012) and a Scottish Informatics and Computer Science Alliance Distinguished Visiting Fellowship (2010 & 2015). Prior to returning to her alma mater, she was a professor for 7 years at the University of Colorado Boulder. She earned her PhD and MS at Indiana University Bloomington in computer science and her BS in computer science at Eckerd College. She was a National Physical Science Consortium Fellow at Indiana University and a Ford Apprentice Scholar at Eckerd College.

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