Provocations for Reimagining Informatics Approaches to Health Equity

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Summary

As the informatics community commits to the goal of advancing health equity, it is essential that we openly critique our current approaches and reimagine the ways in which we design, implement, evaluate, and advocate for policies related to informatics interventions. In this paper, we present five provocations as a starting point for building more conscientious informatics practice in service of this goal: 1) Health informatics interventions can create an "illusion of impactful action" without significant material benefits for marginalized patients, families, and communities; 2) Health informatics interventions target the wrong stakeholders, the wrong processes, and the wrong technologies to achieve equity; 3) Informaticians must conceptualize health literacy and other factors shaping patients' experiences as a system-level rather than individual-level characteristic; 4) Informatics interventions wrongly assume that interacting contextual factors can be meaningfully captured by over-simplified structured variables; and 5) Informatics interventions often specify the wrong system boundaries and solution space. We further assert that drastic shifts in our current practices will allow us to honor our claims of valuing patient-centered approaches, especially for marginalized communities.

1 Introduction

The last few years serve as an inflection point for informatics interest in questions related to health equity. This interest was catalyzed by widespread inequities witnessed during the COVID-19 pandemic, and it has been repeatedly reinforced by long-overdue healthcare and policy attention to social inequities' contributions to differential health and well-being. Such inequities persist across multiple axes of marginalization, including race, ethnicity, caste, sexual orientation, gender identity, age, disability, socioeconomic status, geographic location, and others.

The theme of the 2022 IMIA Yearbook of Medical Informatics reflects the informatics community's growing commitment to advancing health equity through our approaches to designing, implementing, evaluating, and advocating for policies related to informatics interventions. Unfortunately, to date, the overall contributions made by the informatics community have at best fallen short of their potential, and at worst have reinforced or introduced sociotechnical conditions that perpetuate inequity.

Patient portals and other telehealth systems are emblematic of this problem. As a field, we might imagine that these technologies are inherently capable of reducing health inequities. Yet, such a belief is not supported by evidence. Uptake of patient portals and other telehealth systems are differential according to socioeconomic status, race/ethnicity, age, disability or chronic conditions, and language spoken [1,2]. Contrary to common perception, these technologies do not reimagine the relationship between patient and technology, but rather build upon the inequitable systems already in place. They preserve structures that foster inequity (e.g., financial arrangements) and avoid confronting the variables that must be meaningfully addressed to eliminate inequity (e.g., differential broadband access, educational background, accessibility needs [2–6]). As illustrated by this example, reducing health disparities through informatics is only likely to be realized through open critique of our current approaches coupled with a reimagination of informatics practice. In this paper, we explore these ideas through five provocations, asserting that a more conscientious informatics practice is essential to advancing health equity [7].

2 Provocation 1: Health informatics interventions can create an "illusion of impactful action" without significant material benefits for marginalized patients, families, and communities

As exemplified by the case of patient portals and other telehealth systems, the interventions we design and advocate for may be assumed to have greater material benefits for marginalized people than is realized in practice. Many patient-facing informatics interventions focus narrowly on providing their users with access to information to facilitate decision making and to promote

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valued actions. In the United States, there have been a host of policies that stimulated the tracking and provision of information to patients. For example, beginning in 2005, Medicare reporting of healthcare facility quality indicators (e.g., "Care Compare" [8]) has grown to reporting over 150 indicators. This initiative leverages Medicare funding to incentivize reporting of quality metrics that are made public [9]. The HITECH Act also used Medicare funding to incentivize release of data to patients through patient portals.

On the surface, these policy initiatives appear to make information available to patients and to facilitate their expanded engagement in health care. However, these policies have often failed to meaningfully achieve either impact for marginalized patients. The ways in which these data are presented impose significant health and technology literacy burdens, making them inaccessible to many patients. Moreover, even if consumers are able to access and understand healthcare quality information, they may not be able to act upon it. For example, a study of interhospital transfers for patients with acute myocardial infarction (AMI) found that community hospitals (including those in rural areas) transferred preferentially to tertiary hospitals with which they had established financial relationships [10]. Moreover, patients and their families had little opportunity for input into selection of the destination hospital despite the ethical obligation to obtain informed consent while providing fast treatment [11], as well as the interest of some patients to provide input into their care decisions even in emergencies. The result was an "illusion of impactful action" in a context in which information was provided, but in which there was limited policy support, either in its formulation or in its implementation, to facilitate hospital selection for patients and their families. This observation is important since interhospital transfers are a centerpiece of AMI care, quality indicators vary greatly, and there are often multiple nearby options [10].

This example reveals a key problem: we often assume impactful action is simply making information available to patients without addressing the constraints of the decision and action contexts in which that information is being provided. Informaticists should work with marginalized patients, families, and communities to determine how information can be provided in ways that are meaningful and understandable to them. Furthermore, for patients and their families to fully act upon the information provided, we must also create meaningful opportunities for participation. This means that we should also work with institutions like healthcare systems, and dismantle any systems that reinforce power dynamics that disadvantage or silence patients, families, and communities. Creating impactful action, therefore, requires patient-facing informatics solutions to be formulated without an assumption of the inherent benefit of information, but rather with a critical lens that looks holistically at what the goal of providing information is and that collaboratively addresses the multiple barriers to achieving that goal.

3 Provocation 2: Health informatics interventions target the wrong stakeholders, the wrong processes, and the wrong technologies to achieve equity

Advancing health equity through informatics also requires re-examining the level at which we intervene. It is well known that health and healthcare disparities emerge from the social determinants of health, or the settings in which people are "born, live, learn, work, play, worship, and age" [12]. This includes meso-level factors such as living and working conditions, social and community networks, and health systems. In turn, these meso-level factors are shaped by macro-level social and political contexts, and processes of marginalization [13]. In this framework, individual-level psychosocial issues, behaviors, and biological factors are shaped by these meso- and macro-level factors and vice versa.

"Upstream" interventions intervene earlier in the chain of influences that produce health disparities, such as through macro-, meso- or multi-level interventions (i.e., those that simultaneously address two levels, such as interventions operating at both the individual and community level [13]). "Downstream" interventions, by contrast, focus solely on individuals (mostly patients), and may attempt only to reduce consequences of poor health. Much published equity-focused informatics research focuses on individual-level interventions [14]. Such a focus is unsurprising given the deeply engrained patterns of thought and structures in some countries that assume individuals are the important social unit of analysis, that each acts freely within various markets to express preferences, and is the bearer of certain individual rights guaranteed by the state. However, there are flaws in relying solely on individual patient effort and choice as intervention mechanisms, since this can produce intervention-generated inequity [15].

Pursuing meso-level and multi-level interventions requires us to investigate the roles of meso- or macro-level factors in health disparities, and then to ask "who, or what, has agency over this problem?" In research on HIV testing among gay, bisexual, and queer men, we found that social network-related factors, especially stigma, accounted for more of the variance in having a recent HIV test (as per CDC guidelines) than often-targeted individual-level psychosocial factors like perceived risk and perceived behavioral control. A further study revealed that social media was a major setting in which HIV stigma was enacted [16], and that stigma may even be amplified in these online environments. Given the implications of this for HIV testing decisions, this research suggested the potential value of interventions that target the social media context to reduce HIV stigma, which may in turn help to reduce barriers to HIV testing [16]. If successful, a benefit of this approach would also be that it would reduce the burdens of navigating stigma while seeking testing. As this example illustrates, our interventions may be more impactful if we generate technological interventions that respond to the full range of individuals' lived experiences [17], and that operate at levels beyond the individual, such as the social network or community [18]. As we grow our practice beyond a focus on the individual, we should also orient our practice to addressing even more macro-level structures which shape patient experience, such as corporate profit maximization, patriarchy, ableism, racism, stigma and other forms of social marginalization and stratification.

4 Provocation 3: Informaticians must conceptualize health literacy and other factors shaping patients' experiences as a system-level rather than individual-level characteristic

Moving beyond a focus on individual level factors further necessitates challenging our assumptions about what characteristics operate at an individual level versus at a systems level, and consequently reconstructing our approaches to address these characteristics. For more than 30 years, the ability to locate, interpret, and use health information has been termed "health literacy." Health literacy has generally been thought of as a combination of skills and background health knowledge. Assessment instruments have been developed to identify health literacy deficits, and interventions have been developed to assist people with low health literacy. This work has all centered on the idea that health literacy is a characteristic of an individual [19–22].

And yet there have always been indications that people with lower levels of formal education and those who score poorly on literacy assessments can, in fact, act in a literate way - accessing, understanding, and applying health information - when the information is designed for their needs and goals. As one example, medication instructions are followed more accurately when the confusing "2 pills twice daily" is rephrased as "2 pills in the morning and 2 pills at night" [23, 24]. Patients can follow health instructions when they are written in plain language and appropriately illustrated, or when they work with providers who receive communication training.

Historically, these findings were interpreted to mean that a patient's fixed skill level determined what complexity of information they could use. However, it's becoming clearer that the patient's skill is not the determinant of the effectiveness of communication. Instead, communication can be effective when communicators present information appropriately for the cognitive skills and goals of the patients. Communication can also be effective when health information materials are designed effectively enough for patients' needs. It is the match between information recipients, information communicators, and information artifacts that determines whether communication can occur [25].

This systems perspective is reflected in the US Department of Health and Human Services (DHHS) 2019 redefinition of "health literacy" in the HealthyPeople 2030 initiative [26]. Health literacy is no longer the degree to which individuals can obtain, process, and understand basic health information. Instead, health literacy "occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions."

This perspective needs to be adopted by informatics. Instead of enumerating the literacy or skill deficits of the users of our technology, we should be focusing on how to address our own deficits as communicators and information system designers. Such a perspective should also be adopted beyond the domain of health literacy to encompass other barriers to meaningful engagement with informatics solutions, such as technology literacy, usability, language preference, and cultural values and beliefs [27].

5 Provocation 4: Informatics interventions wrongly assume that interacting contextual factors can be meaningfully captured by over-simplified structured variables

In recent years, a major equity focus for health informaticists has been gathering, processing, and using data concerning patient social determinants of health. This widespread effort has been motivated at least in part by introduction of value-based healthcare financing models in the United States, which compensate based on health outcomes rather than on the volume of services provided. This focus on outcomes has highlighted the fact that medical care is not the largest determinant of health outcomes, which are also strongly influenced by "...adverse social conditions associated with poor health, such as food insecurity and housing instability [28]," as well as vulnerability to violence, incarceration, and environmental degradation. Screening programs ask patients to report their social risks [29]. Any risk that a patient wants help with is defined as a "social need." Ideally, screening data can be used to either adjust care or provide supplementary assistance for patients [30].

Typically, screening instruments standardize data collection, or "render…things uniform [31]" across time and space. Social needs data are typically recorded via templates as structured data, which is easier to search and aggregate. Structured social needs data are subject to commensuration, which involves "...comparison of different entities according to a common metric" [32]. The resulting measures may be risk scores such as those that compile multiple measures for purposes such as identifying patients for whom increased healthcare spending is expected.

The prominent motivations driving the collection of social needs data have resulted in over-simplified ways of capturing data, which are not oriented towards improved patient care. Typically, these data elements simply capture whether or not a patient has a social need related to a particular social determinant of health, rather than capturing any data about the nature of that need, nor the ways in which these needs are interrelated–which is important for assessments of risk and feasibility that inform patient care [33]. Without this more nuanced information, either captured through significantly more detailed structured data or through narrative, it is at best difficult and at worst impossible for clinicians to address these broader contextual realities shaping patient health and well-being. For example, a patient may indicate experiencing barriers related to transportation, but such a barrier might arise from underlying financial barriers, disability, lack of adequate public transportation options, distance from a clinic, or a multitude of other interacting realities. Capturing such data in a more nuanced, structured form not only facilitates better patient-centered care, but also allows for aggregation of data about a patient's social needs that can facilitate action at higher levels (e.g., addressing a community's lack of public transportation).

Moreover, the elicitation and capture of valuable narrative data, which allows clinicians "to understand the meaning and significance of stories through cognitive, symbolic, and affective means," fosters empathy and stronger clinician-patient relationships [34]. Details of stories and connections between events in those stories can further help clinicians disrupt assumptions about the simple cause and effect and instead realize the synergistic, cumulative effects of interacting social determinants of health in which a patient is embedded. Moreover, it can help clinicians to appreciate patients' strengths, as shown in the significant efforts that marginalized patients may expend in order to manage their health in the face of systemic barriers [35].

As we recognize and formulate informatics interventions oriented toward capturing data associated with inequity, it is essential that we capture it in ways that are fully oriented towards improving patient care. We should work with both clinicians and communities to determine what types of data to capture, how such data should be captured, and how such data should be translated into information that may be easily acted upon. Without such actions, we risk everything from workarounds, such as efforts to maintain a narrative alongside simplified, structured data elements in free-text parts of templates, to a complete failure to capture necessary aspects of a patient's circumstance and story, which are essential for high-quality care [36].

6 Provocation 5: Informatics interventions specify the wrong system boundaries and solution space

Those of us who engage in community-based participatory research and practice regularly note that engaging in deeply community-grounded efforts is essential because it allows the community to define the problem of focus and the form of the informatics solution [37]. The challenge here, however, is that when we enter these conversations assuming that the only form a solution can take is one that is technology-based, we not only constrain the solution space but also constrain the types of problems with which we are willing to engage. As a consequence, we may work with community members on a problem that is not a priority for the community and we may generate a solution that is not the best fit for the community [38]. Moreover, the solution may be the best technological solution for the community, but a technological solution may not have been the best overall solution. Thus, in engaging in even the best participatory processes for informatics work, we may be unintentionally contributing to perpetuating systems of disadvantage by directing efforts away from the most pressing problems and by designing and implementing solutions that fall short of the community's needs.

One way forward is to approach our work as informaticians within the context of larger multidisciplinary teams (e.g., health sciences, social sciences, engineering, public policy, law) that engage in long-term building of relationships with each other and other community partners. Such broader engagement welcomes conversations about what problems are priorities for the community without constraining the types of problems discussed by disciplinary expertise. It simultaneously allows for the types of solutions developed to take on multiple forms in two ways. First, with many voices in the room across disciplinary expertise and lived experience, solutions may emerge once again in ways that are not constrained by singular expertise. Moreover, long-term engagement leads to the building of trust and for team members to say that a particular form of solution being proposed is not the best fit. As informaticians, this requires accepting and even embracing that we may enter conversations in which a traditional informatics solution will not be centered or that the technological component of a longer-term solution may emerge later in the relationship, or that the technology component needed was so simple that it might not advance our professional goals of getting published or funded. Thus, an informatics mindset may contribute to a conversation even if informatics technology is not central to a solution. This understanding, however, is something that should be celebrated if we take the view that we only want to create solutions that are of real benefit to communities.

7 Conclusion

As do other actors within the healthcare ecosystem, we value patient-centeredness as a key goal. Yet, these provocations may be seen as a means of calling into question our current approaches to adhering to that value, particularly for patients from marginalized communities. Instead of patient-centered, many aspects of our current approaches may be viewed as technology-centered. Similarly, many of our current approaches may be seen as falling short of being patient-centered by failing to adequately account for the patients in context and by focusing on the individual rather than on other system factors as the focus of intervention.

It will be essential for the informatics community to directly attend to the issues raised by these provocations if our community is to realize its potential to contribute to the advancement of health equity. In all of our efforts, we must be committed to questioning our shared assumptions about the inherent benefits of information and technology, and the ways in which such interventions are typically conceptualized and implemented. These provocations emphasize the need for drastic shifts in our typical ways of practicing informatics. Movement in directions suggested by the provocations should be catalyzed by deep engagement across disciplines and by marginalized people and communities in all our efforts, leveraging techniques ranging from community-based participatory research [37] to citizen science [39]. Finally, ensuring that suboptimal solutions do not persist or proliferate will require early and consistent monitoring of both intended impacts and unintended consequences.

Health equity is finally a part of mainstream conversation. Advancing it requires us to reimagine many aspects of systems shaping health and well-being. To contribute to the advancement of health equity, the informatics community must also engage in this reimagining.

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