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Towards Developing an eHealth Equity Conceptual Framework

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Abstract. Early implementation of electronic health records and patient portals had great promise of addressing the widening disparities in health. However, recent research has found that not only are these disparities persisting, but the differences in health outcomes between populations are increasing. Addressing this gap specific to ehealth calls for attention to health equity. Health equity approaches reveal the systematic and societal structures that contribute to preventable and unjust outcomes for different populations. To conceptualize and apply a health equity approach within ehealth, we propose the eHealth Equity Framework (eHEF). Derived from the World Health Organization's conceptual framework for actions on the social determinants of health, eHEF can be useful for public health practitioners, researchers, policymakers and information technology designers to keep health equity agenda at the forefront of all stages of health information technology lifecycle.

Keywords. digital divide, ehealth, health equity, health disparities, health information technologies (HIT), patient portals, social determinants of health

1. Introduction

Equity in health is achieved by targeting health disparities, defined as potentially avoidable, systematic differences in health between groups of people who are differentially (dis)advantaged socially [1, 2]. In the context of ehealth, health equity acknowledges the complex factors (e.g., socio-economic status, gender, ethnicity, race, digital divide, health literacy) that can lead to the unequal provision of care and unfair differences in health outcomes. In the United States (US), health equity has been declared as a foundational goal within the development and implementation of patient portals. The US Institutes of Medicine report '*Crossing the Quality Chasm'* (2001) references equity as one of the six aims at the core of rebuilding healthcare delivery [3]. In Canada, where patient portals are in the early stages of development and implementation, policy documents provide limited examples of bringing together concepts from ehealth and health equity [4]. Within the academic literature, frameworks addressing chronic disease, health literacy, and social determinants of health, have been extended into ehealth models with a potential to target health disparities [5-7]. Each of these factors are significant to conceptualize health equity within ehealth context, but on their own are not sufficient in addressing inequities inadvertently perpetuated by health information technologies (HITs). Although there has been increased recognition of health equity within ehealth

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literature and practice, we were unable to find a framework that provides a comprehensive conceptual resource for considering health equity in ehealth interventions.

We contend that in order to systematically study, understand, and influence how patient portals (and other HITs) are helping to achieve equity in health for diverse populations of HIT consumers, especially for patient groups bearing the highest burden of disease and illness, a comprehensive and theoretically-robust framework / model is needed. In this paper, we will present our initial attempt to derive such a model, the *eHealth Equity Framework (eHEF*). We will use examples from research on patient portals to introduce and demonstrate eHEF's application in research, policy and practice.

2. The eHealth Equity Framework

Our eHealth Equity Framework (eHEF) (see Figure 1) arises from the public health perspective. eHEF builds upon the World Health Organization's "Conceptual Framework for Action on the Social Determinants of Health" (CSDH) [8, 9] and brings together the concepts of health equity, social determinants of health inequities and ehealth. In Figure 1 the underlined text and dotted arrows indicate the changes to the original framework. We first describe some key assumptions of the CSDH focusing on concepts that are either shared or distinct between the two frameworks. We then proceed to discuss various components of eHEF with references to the original CSDH.

2.1 Background

CSDH takes a life course perspective in recognizing how social, economic and political context influence health outcomes. It represents concepts that are shared within health equity and ehealth literature: governance, policy, education, occupation, income, gender, ethnicity and race, behavioral, psychosocial and biological factors. CSDH also offers considerations that may be less recognized within ehealth interventions, particularly societal and cultural norms and values and material circumstances. CSDH focuses on the distribution of health and well-being (Figure 1; right box) and

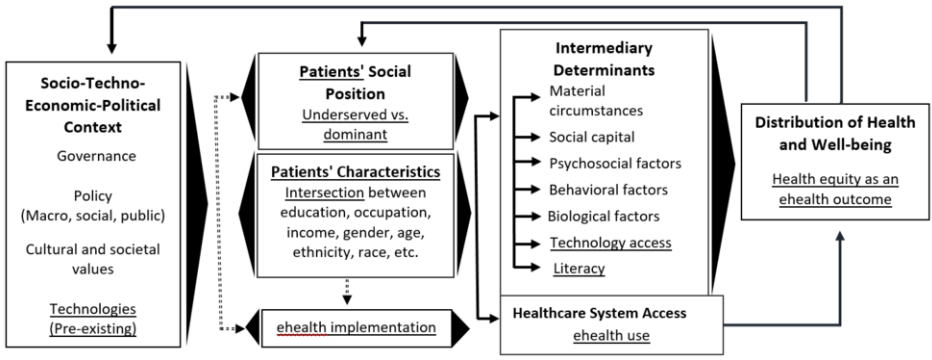

Figure 1: eHealth Equity Framework (adapted from Solar & Irwin, 2007)
Underlined words and dotted arrows indicate changes from original model

emphasizes how the delivery of an intervention can generate different outcomes between populations; thus suggesting the necessity of applying a health equity lens from policy through to practice. The large triangular arrows attached to the boxes are preserved from the CSDH, and represent direction and magnitude of the mechanisms that influence the distribution of health and well-being. The thin arrows create feedback loops, suggesting that the framework is not to be interpreted as a linear model, but as a web of relations.

Importantly, in the original CSDH framework, technology is not viewed as a distinct concept. Indeed, CSDH was intended to shift away from the predominant "technology-based medical care", and acknowledge the broad social processes that influence patient outcomes [9]. In contrast to the absence of technology in the original socially-focused CSDH framework, we have integrated technology throughout eHEF (see Figure 1). Although a full exploration of this integration is beyond the scope of the paper, there are three important considerations for arguing that the technical and the social are not mutually exclusive: 1) Equating technology with predominant medical care models, although commonplace, limits an examination on how technology can apply to, or even is intrinsic to, social models of care. We suggest that CSDH's assumption about technology dichotomizes the social and the technological in a way that is theoretically and practically problematic [10]. This assumption also discourages an examination of health equity within ehealth; 2) Solar and Irwin, the authors of CSDH, justifiably critique medical models that overlook the role of social structures for health and wellbeing [9]. Their argument can be extended to ehealth: we should be attentive to the risk of technological interventions that are intended to improve patient outcomes, but result in supporting the dominant, already healthier populations; and 3) The CSDH framework was conceptualized during the emergence of social media, and thus the relationship between information technology, health and social processes may not have been fully realized during conceptualization. In the past decade, there has been increased recognition that technology can be a determinant of health, and yet also applied as a strategy to address health inequities [11, 12].

Thus, to reflect the complex intersection between ehealth and health equity, technology has been conceptualized throughout all eHEF stages. Matching with the life course perspective of CSDH, the lifecycle of information technologies has been incorporated throughout each stage of eHEF, from the pre-existing technologies, through to implementation, use, and outcomes. We are drawing on Silver, Markus and Beath [13] to define various stages of ehealth life cycle: pre-existing technologies refers to the existing technological infrastructure that can be both enabling and constraining for different patient populations. Implementation refers to the initiation, acquisition, introduction and adaptation stages. Use refers to who uses the system and for what purpose, while recognizing the unintentional and differing individual consequences of this use. Outcomes are specific to equity, and can be applied both proactively in designing equitable ehealth strategies, and reactively to evaluate distribution of health and well-being after ehealth implementation.

2.2 Socio Technical Economic Political Context

The left of Figure 1 indicates the socio-techno-economic-political concepts that are often conceptualized within health informatics as system-level considerations: policy, governance, cultural and societal values and pre-existing technologies. Patient portal-specific policy examples include the '*US meaningful use legislation for electronic health records*' and clinical guidelines that have informed the development of electronic health

records (EHRs). Governance represents how each country, province, state or medical clinic may administer, manage and interpret policies and guidelines to support health care practices. A distinction within eHEF is that it is foremost an equitable model of care, with an ideal outcome being patient-centered care, where *all* patients are respected. Governance structures guided by patient-centered care may not necessarily lead to equitable outcomes, as they may represent the values of the dominant patient population. Governance processes and policies sensitive to health equity concerns, would involve ehealth strategies that move beyond blanket approaches, and recognize that additional resources should be dedicated to underserved populations. This perspective, where health is viewed as a "collective social concern", demonstrates a particular value. How this value is enacted by society can impact what supports are dedicated to different populations and illness groups. Stigma and discrimination may be perpetuated when a society views health primarily as an individual's responsibility while not acknowledging the influence of socio-techno-economic-political processes. The relationship between values and ehealth is demonstrated by patient portals use by people with HIV. The historical and ongoing stigma towards this illness has resulted in limited use of patient portals due to concerns of potential confidentiality breaches in having sensitive health information online [14]. An ehealth equity perspective recognizes the specific barriers in use of patient portals for people with HIV and includes strategies to address these concerns: building trust in the technology through policies specific to security protections, and limiting how online records are reported that may inadvertently disclose a diagnosis to family members [14].

eHEF adds '*technologies – pre-existing'*, to acknowledge the influence existing technologies have on the implementation of emerging HITs. To use patient portal as an example there are technologies internal (e.g. EHRs) and external (e.g. broadband internet) to the healthcare system that determine which populations may receive the greatest benefit in terms of quality of care and outcomes. As EHRs were designed by and for educated, white professionals, and presuppose high level of literacy and skill, there is a risk that patient portals will embrace the language and preferences of a population with the highest levels of education and socioeconomic status [15]. An ehealth equity approach would acknowledge the significance of these foundations, and develop policies that not only view equity as an overarching goal, but provide strategies throughout all HIT stages to address how these foundations impact underserved populations.

2.3 Patients' Social Position and Patients' Characteristics

The second set of left-most boxes (Figure 1) represent factors often categorized as the social determinants of health: examples include education, occupation, income, gender, age, ethnicity, race and geographic location. Research on patient portals commonly measures and reports demographic factors as indices of health inequities, potentially implying a deterministic relationship between "personal" characteristics such as race and portal utilization. However, in CSDH an important distinction is made by referring to these characteristics as 'social determinants of health *inequities*'. That is, rather than considering determinants as being 'personally-entrenched', they are recognized as socially-mediated factors. Consequently, the emphasis is on addressing unjust conditions that result from social processes [9].

Building upon this, and to prevent misinterpreting these demographic factors as individual and unavoidable predictors of health outcomes, in eHEF we have opted to emphasize equity rather than social determinants of health. '*Intersection*' has been added

to connect these determinants of health inequities within 'patients' characteristics'. We aim to reflect the complexity of these factors, and to discourage applying them as a series of check-boxes. 'Patient' has been added within this section to emphasize that it is patients' social position and characteristics that should be prioritized, rather than dominant voices from traditional healthcare stakeholders. The added dotted arrows further indicate the relationship between the three boxes: when patients' social position and characteristics are not considered during ehealth implementation, marginalization may be reinforced for populations that are already underserved. Ehealth equity interventions sensitive to these concerns would involve implementation strategies that allow for customization to the needs of different populations. For patient portals this could be having an adaptable design where reading level and information can be individually tailored to match patients' characteristics [16].

2.4 Intermediary Determinants Of Health

The second set of boxes from the right in Figure 1 represent factors that CDSH references as the intermediary determinants of health. Healthcare system access is included to emphasize its role in being a health determinant. Often perceived at the individual level, other determinants include biological, psychosocial and behavioural factors. Material circumstances represent the financial means in obtaining a safe physical environment, healthy foods and warm clothing [9]. Not commonly recognized within ehealth, this "consumption potential" provides distinct insights for consumer health informatics, in considering where one lives and what one can afford can impact ehealth use.

While different iterations of CSDH have included the concepts of social cohesion and social capital, we opted for social capital in eHEF. Social capital aligns with shared decision-making approaches in developing trustful and cooperative relationships, while acknowledging the power differentials that are introduced at the socio-economic and institutional level [8]. Two specific additions within eHEF are technology access and literacy, to represent the crossover between health equity, health literacy and digital divide in considering how health disparities may be conceptualized. The analysis of these concepts is beyond scope of this paper, however, both health literacy and digital divide have been considered in the development of eHEF. Although both of these concepts are familiar within ehealth literature, health equity was selected as the overarching concept within eHEF in order to capture the complex relationship between system-level processes, health, information and technology. Literacy forms a distinct category within this section to reflect how system and societal processes influence the multiple forms of literacy (i.e. health, information, computer, media, numeracy, and science literacy) [6]. Literacy was chosen over health literacy, to emphasize that literacy required to effectively use HITs is far more complex than educating and developing skills in understanding purely health-related information [17]. Also of note in this section is that *access* has been referenced in terms of both technology and healthcare. Whereas technology access may include access to the internet, a computer, digital technologies, etc., it is not synonymous with healthcare access. This separation allows for awareness of how information technologies outside of the formal healthcare system can influence health outcomes, and how enrolment, use of patient-centered HITs requires considering personal access to technologies.

3. Conclusion

eHEF is intended to provide a frame to think comprehensively about a multi-faceted health equitable approach across all stages of the HIT lifecycle. For example, the preliminary model is being applied in a scoping review we are currently completing on *'how patient portals are addressing health equity'.* This is how one can apply an ehealth equitable approach using Figure 1: locate the HIT stage within eHEF, extend to the factors within the shared section, and then follow the arrows to understand the broader considerations. Through this process it can illuminate the proximal factors that need to be incorporated to address health inequities, while also drawing attention to possible unintended consequences through distal interactions.

eHEF can be of benefit to: 1) policy-makers in developing ehealth equity strategies with populations that are experiencing health disparities; 2) researchers in not only applying HITs for measuring the social determinants of health, but in evaluating how HITs impact the digital divide; 3) public health decision-makers in not viewing technological and social processes as a dichotomy, but considering how ehealth applications can address health inequities; 4) health providers such as physicians, nurses, and allied personnel in being mindful of health disparities in the context of using HITs; 5) HIT designers in recognizing how the foundations of pre-existing technologies, and patients' social position need to be explicitly considered in ehealth implementation and; 6) patient populations that experience the poorest health outcomes, by revealing how socio-techno-economic-political processes need to be acknowledged in order to achieve equitable distribution of health and well-being.

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