Assessing the Effectiveness of Patient-Engagement Tools in Enhancing Representation in Healthcare Systems

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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1. Introduction: Patient Engagement in Pursuit of Equitable Health Outcomes

Patient Reported Outcome Measures (PROMs) have become an increasingly popular method of engaging with patients with a health condition by assessing their feel and function. Data collected from PROMs can then be utilized to shape organizational structures, outcomes, and processes to improve healthcare systems (Chow et al, 2009). However, a high level of support is required to help patients complete PROMs, support implementation, and enter data for paper-based PROMs. Another form of patient engagement that has become increasingly prevalent is M-Health. The World Health Organization (WHO) defines M-Health as "medical and health practice supported by mobile health devices", and M-Health has had increasing adoption in recent years, supporting the prevalence of patient-centered data (WHO, 2011). This data has the potential to improve health accessibility, support greater care delivery, and enhance diagnosis and treatment accuracy (Cunningham et al, 2016). Another barrier between better patient engagement lies in the lack of consensus on the conceptualization of patient engagement amongst communities, resulting in the current unattained potentials for equitable outcomes. I will examine the effectiveness of patient-engaging innovations in the healthcare delivery-space such as PROMs and M-Health in improving patient representation and involvement in health systems by applying a data feminism framework developed by D'Ignazio and Klein (D'Ignazio and Klein, 2020).

2. The Promise and Limitations of PROMs and mHealth Solutions

The growing availability of healthcare data has driven the desire for increased personal care. Efforts have been made in recent years to better engage patients in healthcare systems in efforts to reduce inequity and improve patient-centered care. The use of PROMs has been found to enhance communication between individuals and care providers, ensuring that healthcare decisions are sourced from collaboratively-identified patient needs while also increasing discussions about patient experience, and uncovering undiagnosed patient health states and preferences (Rutherford et al, 2021).

Both PROMs and m-Health strategies aim to utilize individual health data with the intention of centering care around the patient. Many frameworks have been developed in efforts to evaluate equitable practices in data-driven systems. To investigate the strengths and limitations of various patient-engagement strategies in increasing equity in healthcare systems, the data feminism framework described by Klein and D' Ignazio will be applied in the following evaluation. The Data Feminism framework ascertains that those who work with data should: (1) Examine power (2) Challenge power (3) Elevate emotion and embodiment (4) Rethink binaries and hierarchies (5) Embrace pluralism (6) Consider context (7) Make labor visible (D'Ignazio and Klein, 2020).

The true representativeness of the PROMs process is examined upon an interrogation of patient-engagement data that may be left out of the PROM process. A high level of support is required to help patients complete PROMs, support implementation, and enter data for paper-based PROMs. As a result, the data collected from PROMs is likely to exclude invaluable data of communities that lack adequate resources for PROM collection and potentially improperly prescribe unrepresentative treatments in effect. While PROMs were found to increase the effectiveness of triaging patient care, the patient-responsibility of providing subjective-experience based health state descriptions has the potential to worsen existing cultural, racial, or gender-based disparities as stigmas may inhibit marginalized groups to inaccurately or under-report health states or outcomes. An illuminating study utilized data from the 1995 Detroit Area Study, where various subjects were asked demographic information and level of perceived discrimination in their life, as well as self-reported ill days and bed days (Williams et al., 1997). It was found that even after accounting for socioeconomic factors, perceptions of discrimination incrementally contribute to racial disparities in self-reported health (Williams et al., 1997).

The collection of data from PROMs should be tied to actionable, equitable treatments that fight the existing biases that have led minority individuals to receive unequal medical treatment, despite reporting similar health states as their counterparts. Studies have shown that even seemingly equitable healthcare decisions, such as identical treatments for identical reported symptoms, may result in differential efficacy amongst different ethnic populations (Campbell and Edwards, 2012). Thus, data collection afforded by PROMs must seek to integrate cultural context, with an understanding of the systemic power structures affecting patient care and outcome differentials. Without robust understanding of such context behind the data, the potential benefits for increasing equitable, representative treatment are limited at best, and may even worsen existing disparities through the ignorance of the power dynamics situating collected data.

In addition, the method of the implementation of PROMs will affect the manners in which the data is situated, and the underlying power structures that shape the stories that are able to be shared. Digital implementation of PROMs, while popular in many HIC with advanced, robust digital infrastructure, has the potential to exclude marginalized voices who may be in most need of improved, context-driven care but find themselves excluded due to the digital divide. Equipped with invaluable, patient-reported data, healthcare practitioners must consider the ways in which the provided data is situated in a cultural, political, and social context and the various power differentials that shape data collected. An interrogation of underlying power structures proves necessary in this context for adequately addressing inequities that result from patient-centered data collection processes like PROMs.

Meanwhile, the emergence and rapid growth of mHealth strategies have created a unique opportunity to engage communities. In data from the Health Information National Trends Survey (HINTS), which collects nationally-representative data about attitudes regarding, knowledge of, and usage of health-related information by the American public, racial and ethnic minorities were found to be more likely to use their mobile apps to access health information (Ray et al, 2017). Thus, M-health affords the potential for empowering the voices of the underrepresented, and could equip researchers and practitioners with the ability to create more inclusive, equitable healthcare systems. However, many existing socioculturally tailored mHealth solutions have not embraced a pluralism of diverse perspectives beyond usability studies (Huh et al, 2018). Thus, many M-Health solutions have been developed with a dearth of context, depriving their potential to empower marginalized communities and fight power differentials. Consequently, these have the ability to exacerbate disparities in some communities, while providing incremental benefits to other communities.

Underserved communities may benefit from mHealth technologies, and more generally, consumer health informatics (CHI) as it enables self-management of health at lower costs. While such technology has potential for reducing existing financial healthcare barriers, consumer health informatics (CHI) have not found profound impacts due to lack of usage by underserved communities, whomst have been observed to have slow CHI uptake. Beyond the digital divide, there were several limiting barriers to mHealth adoption, which include low health and computer literacy, challenges in accepting delivered information, unclear context, and poor usability (Huh et al., 2018). It is evident that, in conjunction with policy-backed efforts to bridge the digital divide, there must be concurrent interventions that aim to improve health and computer literacy, instill greater, personalized senses of trust in healthcare systems and practitioners, as well as demonstratively integrating context-driven outcomes. It is important to note that these barriers are asymmetrically larger for disadvantaged communities. As with every solution in the pursuit of an equitable future, we must ground and situate each effort in a manner that affords every individual and community the context they are entitled to. It was identified from a comprehensive study of empirical CHI literature that factors associated with increased CHI usage were user needs for information, proxy-mediated CHI access, and early-user engagement in system design (Huh et al., 2018). While organizational and policy strategies could be deployed to design effective processes and resources that enable greater points of information access, a primary opportunity for improving CHI adoption by underserved populations is by including them early on within the design process. When underserved communities are properly engaged in the design process, they will feel more inclined to use and trust technologies, as they have catered to a plurality of communities that make them feel as though they are indeed part of a collective - a term they frequently find themselves obscured from. Fostering a sense of public participation in an area typically inundated with hierarchy and barriers to access, is integral for long-term efforts of growing a trusting, collaborative relationship between underserved patients and the healthcare system. When examining mHealth solutions, it is important to note that historically, patients are typically not directly involved in the development of mobile health guidelines and that professional assessments of high quality apps therefore do not translate to the view's of patients (Rowland et al., 2020).

3. Critiques of Data in Health and Expertise in Clinical Settings

Understanding myriad engagement shortcomings within patient care, many healthcare organizations have sought to incorporate patient and public involvement (PPI) into existing processes, with the intention of improving care by integrating "the patient perspective." In the democratic assumption, "the patient voice" is conceptualized as a form of representation (Rowland et al., 2017). A focus should be directed towards the singular attitude, which suggests that merely extending a voice to patients is sufficient without carefully identifying that those privileged with involvement in PPI will likely lack the same social and cultural context situating their experiences as others who may be more disadvantaged for receiving equivalent care. Thus, when examining PPI with the goal of improving health equity it is imperative to acknowledge and embrace the innate multiplicity both in rhetoric and in practice. It is harmful to engineer processes and infrastructure on a foundation of binary assumptions in a world where plurality is objectively omnipresent. The result of such actions will inherently be exclusionary and lead to asymmetrical benefits, widening existing inequalities. From the conceptualization of PPI in a democratic frame, issues due to self-selection and overrepresentation of those situated in power are a failure of PPI by distorting a more accurate depiction of patient perspectives.

3a. Broader Conceptualizations of PPI are Necessary to Bolster the Potential of PPI

Much discourse surrounding PPI may be attributed to the lack of clear theoretical and conceptual underpinning of how the patient perspective is able to provide value (Rowland et al., 2017). Three main rationales behind PPI are democratic, technocratic, and emancipatory. The democratic lens conceptualizes PPI as a method of representation, and situates data in a normative manner. In this lens, PPI is engaged with the intentionality of prioritizing ethical and political concerns of PPI (Gradinger et al., 2013). The technocratic lens argues that patients intrinsically have a sense of embodied specialized knowledge, from which experts may learn from. There predominantly appears to be two kinds of specialized knowledge that experts may hope to gain: experiential knowledge or scientifically-engaged public participation. Experiential knowledge situates the public as providing a moral and social lens, and are not interacting with the scientific world (Dyer, 2004). Meanwhile, scientifically engaged public participation defines patient engagement with a standard of being mobilized and scientifically-literate, meaning they are capable of and willing to communicate with technoscientific experts (Dyer, 2004). Thus, it becomes obvious that organizations employing both democratic and technocratic rationales often manifest tensions.

With a clearer understanding of the intricate tensions amongst various conceptualizations of the role patients are able to provide in PPI research, broader definitions of PPI must be adopted by research communities if they wish to effectively promote greater inclusivity. Drawing from parallels within feminist perspectives, emotions and emodiment must be elevated, where information from seemingly non-traditional sources like indigenous or underserved populations are prioritized in data collection and system design. The process of PPI in research implicitly leans on a more inclusive definition of credibility and knowledge, regardless of the lack of consensus on what exactly is credible (Popay et al., 1996).

3b. A Hierarchy to be Dismantled within and by Healthcare Systems: Dynamics Between Experiential Expertise and "Professionalized" Expertise

To better understand how to approach the pursuit of a more collaborative, representative future of healthcare - it may be helpful to consider patient perspectives on their own role in PPI research. In a study done on cancer research participants on PPI, it was found that while many participants in PPI initiatives held the view that experiential expertise would be the reason one would get involved in research, they privilege “professional” types of expertise (Thompson et al., 2012). They supported the dominance of techno-scientific roles within PPI, and also were quick to defer their own experiential expertise towards the professional, certified practitioners (Thompson et al., 2012). It becomes clear that there has been an established power differential in the patient-practitioner relationship, in which patients believe they have some form of experiential knowledge to provide to experts, but that the expertise afforded by their experiences with PPI was lower in the power hierarchy of the professional’s view on PPI.

Within the binaries of the power hierarchy, patients seem to believe that their experiences do not have equal value as those suggested by professionalized individuals. Many participants emphasized the demarcation between professionals and non-professionals in their value judgments on expertise, where some individuals believed their role in PPI did not involve challenging or questioning professionals (Thompson et al., 2012). This asymmetry of power demonstrates limits the extent to which participants in this study were able to provide “different perspectives”. This demarcation is clear when examining the perspectives in which healthcare professionals engage in discourse on the roles of patients in PPI and what individuals should be involved in PPI research. In some cases, study participants expressed that fear of making unqualified claims in front of professionals prevented them from voicing their self-acknowledged experiential expertise (Thompson et al., 2012). Thus, it is clear that historically, patient-practitioner relationships have been tainted with a hierarchical binary, which in turn limits the extent to which patients are able to collaborate with doctors. While it can be difficult to shift binaries that society has purported, PPI initiatives need to emphasize and communicate the value that patients bring into the field not as ancillary or unfounded, but rather as additive, equal contributions towards improving healthcare outcomes and processes. These processes should emphasize the manner in which publics, specifically patients and underserved communities, are valued. Organizations at the macro-level, and practitioners and researchers at the micro-levels, must be intentional in pursuing collaborative outcomes by breaking down practitioner/patient hierarchies. Challenging power in PPI is a necessary piece in the development of equitable healthcare outcomes.

A main opportunity draws upon a gradual shift towards accepting more pluralistic, contextualized, and experiential forms of evidence as valid. This is easier said than done, and will most certainly take a concerted effort between policy experts, healthcare professionals, and activist leaders, and underserved communities alike. While there have been historical examples of effective engagement by laymen with scientific communities, such as with HIV/AIDS activists role in disseminating HIV/AIDS evidence from U.S. clinical trials, those activists understood traditional power dynamics of the healthcare space and employed strategies of “expertification” or “credibility tactics" where they became proficient in scientific discourses, treatments, and terminology (Epstein, 1995). Thus, it was the activists who bore the responsibilities of stepping into knowledge that would increase the likelihood of acceptance by scientific communities. Healthcare organizations and actors must realize that collaboration under stifled, longstanding power differentials inherently breeds collaboration that diminishes the value of the contributions of communities whomst hold less power. Such engagement is by nature exclusionary, as it only assigns value to those whomst are both willing and capable of engaging with scientific populations on terms set by the upper hand within power structures. In many scenarios, those who are least willing or capable of engaging with the scientific community in this way are the ones who are the most underrepresented and underserved. Thus, asymmetrical benefits are inherent to such engagement strategies in which underserved communities bear the responsibility of bearing existing power dynamics. Organizations must not only make efforts to make room for experiential expertise in positivist spaces, but they must also make demonstrative efforts to communicate the value of such expertise to layman and research participants, whomst have traditionally had their expertise discredited in these spaces. When engineering new processes and resources in promoting the use of experiential knowledge, it is imperative that researchers note the context of the experiential data and promote transparency demonstrating the processes behind the data in addition to those who labored over it.

There have also been discussions about “knowledge spaces" for PPI, which would consist of social networks of knowledgeable actors capable of conversing with professionals on equal terms and influencing service provisioning (Gibson et al., 2012). While this conceptual construction of spaces which aims to uphold democratic values possess potential, care must be taken to ensure that existing socioeconomic barriers will not restrict representative participation in such public forums. The aforementioned construction employs the “expertification” approach described by Epstein and the “scientifically-engaged public participation” view described by Dyer. However, if such spaces were constructed on the premise that experiential knowledge had a degree of inherent credibility in the PPI space, a space where social networks of underserved groups were able to engage in discussion on their own terms, these spaces will have newfound potential to influence equitable outcomes.

4. A Key Opportunity to Reconstruct Health Spaces to Enable more Equitable Patient Engagement

In late modernity, social theorists have identified that scientific knowledge has become increasingly contested (Giddens, 1991). With that, science communities have found that they must deliberately labor to earn trust and credibility for their expertise from the people now more so than ever (Collins and Evans, 2007; Gabe, 1995). This has also led to the broadening of credibility and the growth of PPI within spaces that were exclusively "professional" (Giddens, 1991). The increasing politicization of public health presents another factor that accelerates the needs for effective forums between healthcare personnel and laymen. These trends present a key opportunity to leverage changing power dynamics in forums that emphasize each entity as an equal member with the necessity for collaborating to earn each other's cooperation. These forums may be places for civic engagement and can present opportunities for the increase of citizen power (Arnstein, 1996) in spaces traditionally safeguarded by epistemological hierarchies, where layman knowledge was predominantly sanctioned and discredited. As such, there is an accompanying redistribution of power and transparency towards those previously underserved; whomst have historically lived their lives in the margins. These engagements will include accepting inherent discourses and often multi-lateral interests in efforts to integrate contextualized and empirical knowledge that more equitably and effectively benefits the public.

In this space, tools such as PROMs and mHealth solutions have numerous benefits that can be leveraged to support the construction of a more equitable future, when carefully implemented with consideration of existing power differentials and representational barriers. In a system which demonstrates and acts with compassion and empathy towards its historically marginalized communities, trust and collaboration is gradually developed and nurtured, allowing tools such as PROMs and mHealth to have newfound power in promoting equity. When utilized with awareness of limitations and promises, these tools remain effective vessels of patient representation, an effect which will be bolstered by the reconstruction of scientific community attitudes towards PPI value. PROMs provides a platform for healthcare communities to target specific communities with specific queries, which could be used to bolster contextualized research and more equitable patient care. mHealth extends patient engagement to those whomst traditionally are marginalized in health spaces, while also increasing accessibility and the potential for productive dialogue. This provides a continuum of opportunity for layman engagement with scientific communities, gradually establishing greater trust, transparency, and understanding between communities whomst have historically had a strained relationship with the scientific community.

Discourses between groups are to be expected, and the resulting dialogue presents an opportunity for science communities to engage with laymen, particularly underrepresented populations, on more equal footing. Larger scale efforts must be concomitant with the co-creation and maintenance of these spaces of civic engagement if the goal ultimately is to improve deliberate democratic values and increase citizen power. Science communities must change longstanding exclusionary axioms that have discredited experiential pluralities of knowledge, seeking to co-create technologies and ultimately relationships that productively marry discourses between communities with inherently different perspectives. Social science research on the nature and value of lay knowledge must be embraced, and conceptualizations of lay knowledge should be incorporated to improve more accurate, holistic understandings of health (Popay and Williams, 1996). In addition, effort should be taken to construct research questions in a manner that renders the existing discourse on scientific and non-scientific knowledge negligible (Popay and Williams, 1996).

Further efforts must also prioritize and disseminate actionable knowledge assembled by research initiatives that study scientific interactions with the public sphere. Embracing the inherent discursiveness in such a civic engagement forum signals an acceptance of pluralities of knowledge, a rethinking of traditional power hierarchies and classifications, and the challenging of existing, unequal power structures. It is imperative that healthcare leaders examine and challenge power differentials when designing and assessing PPI technology and assets for a plurality of publics. Generating further relationships and resources to translate this continuous discursive dialogue into transformative social action is the next step in shaping a more equitable future of healthcare.

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