Without Qualitative Health Data, Precision Health Will Be Imprecise

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Introduction

The Precision Health movement offers the promise of highly accurate, tailored health solutions for individuals and, potentially, populations. Despite no consensus definition of its scope (Ryan et al., 2021), Precision Health is an emerging way of translating research into practice and has many forms. Genomics, immunology, oncology, primary care, and public health are among the most recognized disciplines essential to Precision Health, but in reality, nearly any field pertaining to medicine and health is key to this movement. In the United States and Canada, the public sector (CDC, 2020; Genome Canada, 2021), private sector (e.g., GE, 2021; IBM, 2021), and universities (e.g., Stanford University, 2021; University of Alberta, 2021; University of Michigan, 2021; University of Missouri, 2021) have expressed a commitment to Precision Health for years to come. In its current state, Precision Health is being driven by the enormous potential of big data and artificial intelligence. The prospect of being able to pool vast quantities of data with diagnoses that were previously validated by physicians has excited the medical community; higher chances of correctly diagnosing patients and predicting their prognoses (i.e., Hudaa et al., 2019), and for lower costs (Chen et al., 2016) than ever before, would be an obvious boon to public health.

In health research, the buzzword big data refers to vast quantities of data being available in centralized databases, including patient charts, electronic medical records, administrative health databases, medical imaging data, and even meta-captures of scholarly literature. One of the most popular ways to rapidly analyze these sources of big data is rooted in artificial intelligence; probabilistic machine learning algorithms (Andres et al., 2018; Borle et al., 2021) are often—although not exclusively—devised by formally trained computational scientists, with strong input from health experts within the sub-field of interest. One of the best, publicly known, examples is through IBM’s Watson supercomputer whereby the artificial intelligence behind it draws upon massive amounts of administrative health data and academic literature, to speed up the onset of cancer treatment by being able to diagnose cancer earlier through predictive techniques (see BBC, 2015; Chen et al., 2016). In short, Precision Health has become almost synonymous with some of the most advanced quantitative methodological techniques and, therefore, incorrectly, often assumed to be linked solely to quantitative data.

From a “10,000-foot view,” qualitative health research does not currently appear to be a key component of this broad Precision Health movement. Even though there have been many advances made over the past two decades, qualitative health research has, unfortunately, not yet overcome the privileged position of quantitative health research (Green & Thorogood, 2018). Medical practitioners and public health officials who may have the ability to translate Precision Health data into practice cannot do so in a complete way if they are not aware of, let alone have access to, the richness within qualitative health research that could change the pathways of care that their patients receive. Unless scholars specializing in qualitative methods make their cases known at their institutions or to government medical and public health bodies, Precision Health research may miss the most precise and informative data that we have: the behaviors, views, opinions, and intimate details of people, among other contextual factors.

Without qualitative health data, Precision Health will be imprecise, and, thus, scholars and practitioners will be missing a key component of knowledge translation efforts and the ability to make an impact on the health of individuals and communities. Here, we provide comments on two potential paths for qualitative health researchers to consider when contemplating their contributions to or involvement in Precision Health.

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An Aspirational Methodological Path to Take: Artificial Intelligence in Population Precision Health

At its core, the artificial intelligence that we are discussing, for Precision Health applications, is the replication, at large scale, and controlled learning of what the qualitative scholars contributing to this journal already do very well, such as the task of coding a set of semi-structured interviews or text and coming up with themes that portray the essence of the data. However, when doing so, on our own, as individual scholars, there is a chance each of us could be a bit off the mark in our analyses due to minor, and conventionally acceptable, error. So, to minimize error, it is not uncommon for small groups of collaborators to test their inter-coder reliability, by conducting a test whereby all collaborators simultaneously code a sample transcript or sets of text. If all collaborators code similarly within an agreed-upon margin of error, then coding, en masse, proceeds. If there are great disparities, the collaborators re-group and discuss their coding scheme and repeat the process. This is actual human intelligence.

Now imagine—in an extreme scenario—if our expertise, and that of hundreds of other qualitative methodological experts, was to be housed in a hypothetical central, big data, database with all of our health-related studies and all of the ways in which we have coded transcripts, text, and photos among other forms of data. Imagine then that a thinly-financed medical research team needs to analyze an important set of qualitative data they have collected on the reason why their patients living with HIV are not adhering to anti-retroviral treatment. By, hypothetically, submitting their data to this central database and then working with a computational scientist, artificial intelligence algorithms could reliably code transcripts from interviews and focus groups they conducted, and even images collected (see Baccouche et al., 2018; Fort, 2016; Sheth & Giger, 2020). Of course, the work completed by artificial intelligence will never result in a complete understanding of the research, but for some, that trade-off could be very important for if researchers need to, or want to, quickly alter patients’ trajectories and medical outcomes. With enough “training data”—or, in other words, a large existing pool of coded data to pull from—the power of artificial intelligence to predict diagnoses and patient prognoses, in conjunction with the physician’s expert opinion, would not be far off.

The problematic aspect of this paradigm shift is the scale of sharing and pooling of more traditional social science qualitative data; enlightening non-qualitative scholars to the difficulties in collecting such data and how its quality is so highly dependent on interviewers, the environment, and even the possibility of standardizing analytic coding schemes are necessary precursors. It is up to scholars, who have qualitative methodological expertise, to convince medical groups and governmental bodies—especially in the case of publicly funded healthcare—to take on this modality of data collection (and hire trained faculty to oversee it) and for scholars to share their data too. In the eyes of computational scientists, the form of data does not matter nearly as much as the willingness of scholars and medical practitioners to incorporate qualitative data into Precision Health—and then, obviously, allowing computational scientists access.

A Practical Path to Take: Qualitative Data on its Own for Population Precision Health

Population Precision Health is, arguably, the least defined aspect of the Precision Health movement. Broad medical interventions, with precision, among the heterogeneity of human populations remain at the core of the current imprecision (see Khoury & Galea, 2016); social science qualitative health research methods can help change this. Qualitative health data hold incredible power, akin to advanced medical imaging. Whereas magnetic resonance imaging combined with 3-dimensional augmented reality scanning pinpoint medical ailments with high degrees of precision and can prevent diagnostic and procedural errors from occurring (Bourier et al., 2013; Samei et al., 2020), arts-based exhibits, ethnography, focus groups, observational research, photography, cognitive interviews, and semi-structured interviews offer insight into the human experience that can identify inequities in, and barriers to, healthcare. Advanced medical imaging is necessary for individual Precision Health; qualitative methods are necessary for population Precision Health.

Qualitative research sampling methods are often criticized for not being representative of populations and thus, not externally valid. As it has become obvious from examples of the impact of our own work employing ethnographic and photovoice methods, the fact that a study sample is not representative of the population as a whole does not mean that it cannot provide value beyond its specificity. For example, in our work, ethnographic and photovoice methodological approaches among people living with HIV/AIDS (PLWH), from a specific clinic in a Missouri town, provide enormous depth as to potentially effective interventions in improving anti-retroviral treatment adherence and quality of medical care based on the perspectives of PLWH (Teti et al., 2020, 2021). By assessing the effectiveness of our research and interventions, and working with others doing similar work in adjacent states, for instance, there is no reason that researchers and practitioners could not incrementally build upon the scale and representativeness of qualitative samples for population Precision Health initiatives. Here, tailoring practical health interventions to well-defined sub-populations could be feasible and expansive with the great utility of qualitative health research data.

Is Precision Health the Right Path for Qualitative Health Researchers?

Exploring how far qualitative health data will take the Precision Health movement in improving patients’ diagnoses,
treatment, and therapy is a worthwhile endeavor sheerly because the upside of bettering the health of people is a noble pursuit. Qualitative data repositories are developing in the social and health sciences (Syracuse University, 2021; University of Washington, 2021; Washington University in St. Louis, 2021), breaking down norms of such repositories being the domain of quantitative data. However, it is unclear the extent to which any of these qualitative data repositories have an interest in the Precision Health movement. With these current circumstances in mind, it may be the ideal time for qualitative health researchers to pool their expertise and consider creating repositories, and entering into data-sharing agreements with health stakeholders or even the institutions housing qualitative data repositories, to begin creating a critical mass of data which could substantively advance the Precision Health movement’s overall objectives. Waiting much longer on emphasizing the critical role of qualitative health research in Precision Health could, inadvertently, leave these highly precise data behind, resulting in less precise healthcare going forward.

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