



How Health Literacy Affects Data and The Community

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Abstract

A conversation around strengthening data with health initiation and health literacy measures.

Keywords: Data Collection, Surveillance, Health Literacy, Epidemiology Methods, Community Education

Introduction

As epidemiologists and health scientists, our goal is to gather systematic macro-level health data that benefits a described population. This process includes labor intensive work such as cleaning and analyzing the variables, understanding the limitations of what was collected, and delivering reports to community members and policy makers. This job is well-supported by additional staff such as program managers who contextualize the weight of the problem on a community and biostatisticians who provide adjustments to the statistical model. Most data collected helps us get a big picture perspective – survey a few participants and extrapolate to those who were not directly asked. This methodology serves us well in identifying trends, upcoming outbreaks, and ongoing community needs.

With the most recent funding changes and shifts that promote more individualized, less informed medical coverage, the standards around data collection must remain precise and beneficial. What happens when the data gets back to the individual level? We've all heard that an individual's daily choices lead to the big changes in their health, but the gap between theoretical knowledge and applied public health is growing rapidly. An individual can be predicted (in an epidemiological model) to have excellent health outcomes based on social determinants of health and still be exposed to their behaviors that in return cause an increased risk to disease. Key variables that are missing from many surveillance datasets are health behavior measures – especially health literacy and patient activation.

Health literacy is “being able to access, understand, appraise, and use information and services in ways that promote and maintain good health and well-being” [1]. How does an individual interpret that

their risk for developing hypertension jumps from 48% to 70% after the age of 60 [2]? What happens after they acquired that knowledge? For example, an individual lives in an affluent zip code, has great health insurance, stable income, and visits the doctor every year. In our social epidemiology model, we define this person as low risk. However, when it comes to annual health screenings follow up – we'll say blood pressure and cholesterol – this individual does not change their behavior. In our health epidemiology, the rising lipid numbers in a CBC blood panel would define this person as high risk and need of intervention.

Adults with limited health literacy obtain less information while at appointments and have an inadequate understanding of complex medication information [3, 4]. Many researchers have found that health literacy to be highly associated with obesity, dietary choices, screening practices, and exercise [5]. It's a risk factor as much as income, zip code, and other social determinants of health, yet it's only collected through one-time specific research questions.

Determining if an individual will engage in a particular behavior is a difficult thing to strategize, but a worthwhile one. The Theory of Planned Behavior (TPB) has been a great public health model to understand an individual's hesitation behind healthy actions. In the TPB, a decision is formed based on an individual's motivational factors to engage, try, and participate in a specific decision [6]. Generally, the stronger the areas of motivation, the more likely a decision will occur. Pairing this with health literacy allows an individual to feel more confident about this decision. Together, this can increase use of preventative health, lower health costs, and lessen emergency hospitalizations [7].

Why is this important?

While this endeavor is burdensome on an already fragile public health system, its equally important and cost-saving. During COVID response, public health staff were motivated to use multiple surveillance systems to discuss outcomes. One of the US largest ongoing health behavior surveillance systems is the Behavioral Risk

Factor Surveillance Systems (BRFSS). Some larger states were able to combine larger metropolitan data with BRFSS and another health dataset – National Health and Nutrition Examination Survey – to bridge data using small area estimates (**ongoing work of the University of Michigan Institute of Social Research**). Combining datasets that include health behavior measures helped identify both hard to reach populations and areas of low motivation.

Lastly, changing the way we collect ongoing surveillance allows the population to be at less risk to themselves when searching for health information. Data scientists with years of experience in knowing what types of decisions can be made on specific systems are no longer the primary interpreters. It's the American public. With our current data mixed with the widely used adaptation of AI and machine learning, our predictive models can be misused and potentially be used in a discriminatory manner. Variables of health that have high correlation are now being interpreted as factual evidence. By creating data that is both informative and easy to understand, we can ensure that the information used is in the populations' best health interests.

Conclusion

Data is not the only tool to make decisions, but it's a very widespread one. It's in our clinical trials that determines who makes a compliant patient to receive a new medication or procedure. It's in our prevention tools as we determine who gets a targeted intervention. It's in our international conversations about keeping endemic infections low so they don't spread to other countries. Therefore, we must continue to strengthen our data collection and workforce to better inform those decisions. If we don't address this missingness in our data, we will constantly fall short of our goal of effective interventions and limit benefits to the population we continuously serve.

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