



February 28, 2017

Learning Healthcare Systems  
Office of the Director, Agency for Healthcare Research and Quality  
5600 Fishers Lane  
Rockville, MD 20857

On behalf of the Center for Data Innovation ([datainnovation.org](http://datainnovation.org)), we are pleased to submit these comments in response to the Agency for Healthcare Research and Quality's (AHRQ's) request for comments on learning health-care systems.<sup>1</sup>

The Center for Data Innovation is the leading think tank studying the intersection of data, technology, and public policy. With staff in Washington, DC and Brussels, the Center formulates and promotes pragmatic public policies designed to maximize the benefits of data-driven innovation in the public and private sectors. It educates policymakers and the public about the opportunities and challenges associated with data, as well as technology trends such as predictive analytics, open data, cloud computing, and the Internet of Things. The Center is a non-profit, non-partisan research institute affiliated with the Information Technology and Innovation Foundation.

Sincerely,

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<sup>1</sup> "Request for Information—Learning Healthcare Systems," Agency for Healthcare Research and Quality, January 12, 2017, <https://www.federalregister.gov/documents/2017/01/12/2017-00548/agency-for-healthcare-research-and-quality>.



## THE IMPORTANCE OF LEARNING SYSTEMS

AHRQ is rightly exploring the value of learning systems in health care. The National Academy of Medicine defines a learning health-care system as one “designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care.”<sup>2</sup> In other words, a learning health system enables health-care providers, researchers, and patients to learn and benefit from the ever growing body of health-care data and knowledge to make ever-more-informed decisions. Such systems are the foundation for precision medicine, which the National Institutes of Health (NIH) defines as “an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.”<sup>3</sup> To deliver personalized treatment, health-care providers must be able to apply new patient data to robust models supported by the latest medical research and historical data, and these providers must also be able to share their results back with the system to ensure these models constantly improve. Thus, a learning health system is necessarily a data-driven health system, and the easier it is for health-care stakeholders to collect, share, and learn from data in a learning health system, the more effective the system will be.

## ELIMINATING DATA POVERTY FOR MORE EFFECTIVE LEARNING HEALTH SYSTEMS

As the world becomes more data-driven, if the public and private sectors systematically exclude certain communities from their data collection efforts, those communities are subjected to “data poverty”—the social and economic inequalities that may result from a lack of collection or use of data. Regardless of how effective a learning health system may be, if the data it learns from is incomplete, non-representative, or otherwise lacking, it will not benefit all populations fairly, improving care for some while leaving behind data-poor communities. The problem of data poverty is not a reason to slow down adoption and deployment of learning health systems, but it does suggest the need to focus at the same time on the problem of data quality and availability.

There are several examples of how data poverty already limits the benefits a learning health system could offer. In clinical trials, for example, data from participants helps the Food and Drug Administration make decisions about whether drugs, vaccines, or other medical treatments are safe and effective.<sup>4</sup> Historically racial and ethnic minorities, as well as women, have been underrepresented in clinical trials.

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<sup>2</sup> Ibid.

<sup>3</sup> “What is Precision Medicine?,” National Institutes of Health, accessed February 28, 2017, <https://ghr.nlm.nih.gov/primer/precisionmedicine/definition>.

<sup>4</sup> Daniel Castro, “The Rise of Data Poverty in America,” Center for Data Innovation, September 10, 2014, <http://www2.datainnovation.org/2014-data-poverty.pdf>.



For example, Hispanics represent approximately 16 percent of the U.S. population but only 1 percent of clinical trial participants.<sup>5</sup> When certain groups are underrepresented in the data, the decisions made about the safety and efficacy of treatments for patients may be biased. For example, women are more likely than men to have an adverse reaction to a drug and may respond differently to medical devices. Some drugs have even been taken off the market because of effects found in women that were missed in clinical trials. Similarly, studies have found that various racial and ethnic groups respond differently to certain medications.<sup>6</sup>

Additionally, considerable health disparities exist between the lesbian, gay, bisexual, and transgendered (LGBT) community and the heterosexual population, yet data that would help address these disparities is lacking.<sup>7</sup> For example, studies have found that compared to their heterosexual counterparts, LGBT youths have a higher risk of suicide and mental health problems. Lesbian and bisexual women are more likely to become obese, and bisexual men and women are more likely to suffer from physical, mental, or emotional disabilities.<sup>8</sup> In addition, the LGBT community suffers from higher rates of depression than the general population.<sup>9</sup> Despite these many pressing health risks, researchers often lack enough data to analyze these issues and develop solutions.<sup>10</sup> Under current law, federally conducted or funded public health programs are required to collect data on key demographics like race, sex, disability status, and ethnicity, but not on sexual orientation or gender identity, preventing health-care researchers and providers from reliably researching and addressing these challenges.<sup>11</sup>

Finally, health care providers do not collect sufficient medical data about mental health. Approximately 1 in 5 Americans suffers from a mental illness each year.<sup>12</sup> While the Health Information Technology and Economic Clinical Health (HITECH) Act of 2009 significantly expanded access to electronic health record systems for many health care providers, it excluded mental health providers from participating in the program. As a result, many mental health providers do not use interoperable electronic health records

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<sup>5</sup> "Clinical Trials Shed Light on Minority Health," Food and Drug Administration, <http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm349063.htm>.

<sup>6</sup> "Successful Strategies for Engaging Women and Minorities in Clinical Trials," Society for Women's Health Research and U.S. Food and Drug Administration Office of Women's Health, September 2011, <http://www.fda.gov/downloads/ScienceResearch/SpecialTopics/WomensHealthResearch/UCM334959.pdf>

<sup>7</sup> "LGBT Health Disparities," American Psychological Association, May 2013, <https://www.apa.org/about/gr/issues/lgbt/disparities-brief.pdf>.

<sup>8</sup> Leigh Evans, Kelsey Lawler, and Sammy Sass, "Gathering Sexual Orientation Data On Statewide Behavioral Risk Factor Surveillance Surveys: A Call To 25 Action For States," The Fenway Institute, March 2014, [http://fenwayhealth.org/documents/the-fenway-institute/policybriefs/COM484\\_BRFSS\\_Brief.pdf](http://fenwayhealth.org/documents/the-fenway-institute/policybriefs/COM484_BRFSS_Brief.pdf).

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> "S.989 – Strengthening Health Disparities Data Collection Act," Congress.gov, <https://www.congress.gov/bill/113th-congress/senatebill/989>.

<sup>12</sup> "Mental Health By The Numbers," National Alliance on Mental Illness, n.d., <http://www.nami.org/Learn-More/Mental-Health-By-the-Numbers>.



and are falling behind other health care providers in using information technology to improve care and reduce costs.

As AHRQ works to advance the development of learning health systems, it should prioritize eliminating data poverty to increase the effectiveness of the systems as a whole and ensure that all communities can reap the benefits.