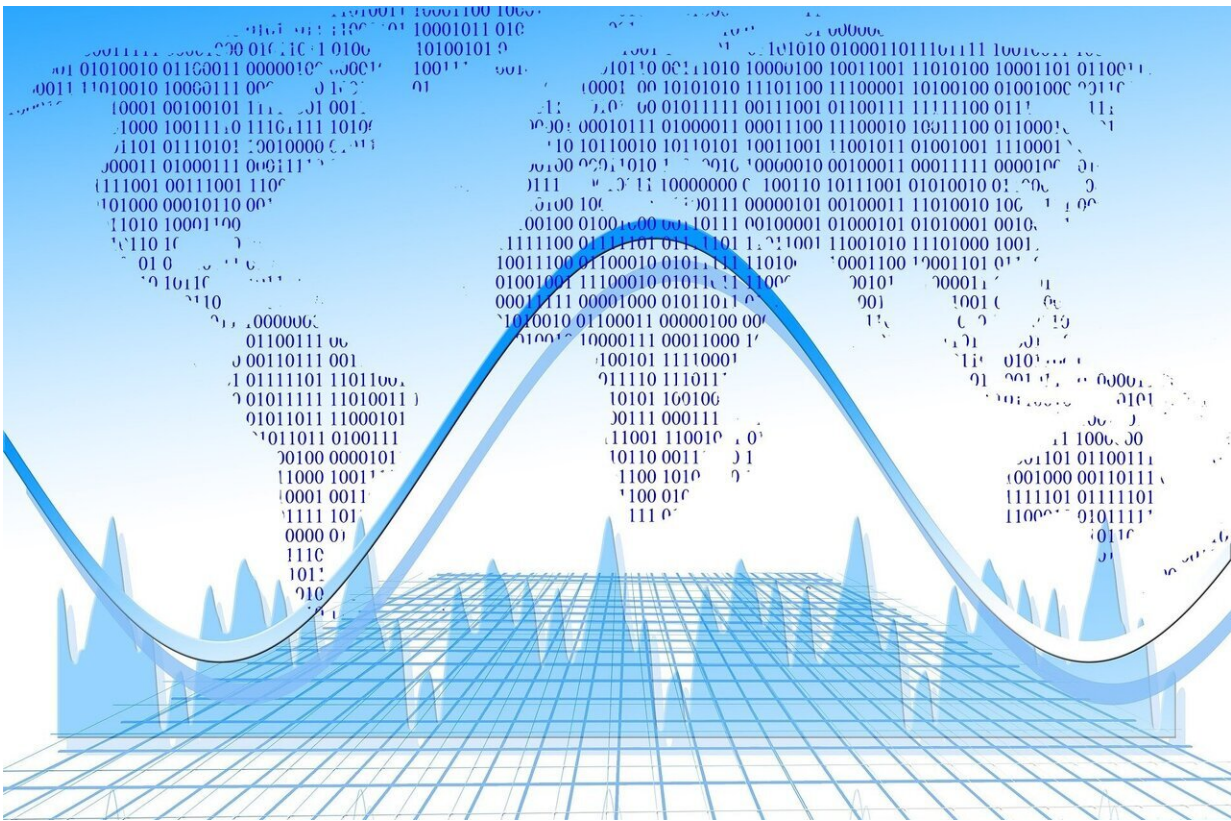# Individual privacy and big data uses in public health

July 13 2021, by Callie Rainosek

Credit: CC0 Public Domain

In the United States, massive volumes of individual-level data, called "big data," are used for a variety of reasons, including marketing, intelligence gathering and political campaigns. Big data are also vital to

public health efforts, such as improving population health, informing personalized medicine and transforming biomedical research. However, it can be challenging to use big data for health applications due to laws and concerns about individual privacy.

Federal and state data-protection laws exist to protect individual privacy, and they vary depending on the type of data, who is using it and the data's intended purpose. The complexity and differences in these data-protection laws can make it difficult for researchers to use big data for social benefits, such as improved public health. Additionally, few laws have a public health or research exception that permits using the data to explore health implications.

"The absence of these data-use exceptions for public health or research can be persistently challenging for researchers and public health professionals," said Cason Schmit, assistant professor at the Texas A&M University School of Public Health. "As a result, research projects and public health practice can be potentially delayed, impeded or become more expensive. In light of current events, the absence of data-use exceptions for public health can also make rapid response in public health emergencies, such as COVID-19, more difficult."

Elected officials determine the laws to permit or restrict data uses, which significantly impact individual privacy and public benefit. Therefore, input from the public is critical to finding the right balance between individual privacy and public benefits.

To explore the American public's preferences for how identifiable data is used, Schmit recently led a study that surveyed more than 500 nationally representative participants, asking them how comfortable they were with different data use scenarios. The results of the study, published in the *Journal of Medical Internet Research*, suggested that the American public strongly prefers that big data be used for public health

and research purposes over profit-driven, marketing or crime-detection activities. The results also suggest that it is strongly preferred that data be used by universities or non-profit organizations over uses by businesses and governments.

However, when it came to the different types of data that may be used, such as economic data, research participants were fairly indifferent.

"Our research findings show that the current patchwork of U.S. data-protection laws does not reflect public preference for individual-data use," Schmit said. "Many U.S. data protection laws focus primarily on the type of data used, but the results of our study suggest that the public is fairly indifferent toward these data distinctions. Instead, the public is more concerned about who is using the data and for what purposes. Based on study results, the public particularly has a strong preference for data uses that promote the common good, as opposed to individual or self-serving interests."

Provided by Texas A&M University