

# Reflections on the Future of Health Data Summit

The Future of Health Data Summit was our second annual meeting of nearly 300 senior leaders across government, payers, providers, life sciences and analytics companies. It's a forum to discuss healthcare challenges and the role connected health data can play to solve them. Across Summit panel sessions, similar themes echoed which included the following key takeaways:

1

## **COVID-19 was a hardship that allowed us to demonstrate what we can do in the face of a massive health emergency. It also revealed glaring U.S. data and technology gaps.**

Fortunately, many data collaborations were formed in response to the pandemic. One panel on innovations emerging from COVID-19 highlighted the FDA COVID-19 Evidence Accelerator, the Covid Research Database and the NIH's National Covid Cohort Collaborative (N3C). Another panel discussed data sharing during COVID-19 noting that an absence of data left us vulnerable during a national health crisis. Scott Gottlieb, Commissioner of the FDA between 2017 and 2019 took it a step further in his closing fire-side chat with David Shulkin, characterizing this gap as a threat to national security (the thesis of his most recent book "Uncontrolled Spread").

2

## **The pandemic shed light on great health disparities in the U.S.**

The fireside chat with Congresswoman Lauren Underwood underscored maternal death rates among Black and Hispanic women while a panel focused on caring for vulnerable populations honed in on patients lost during the "last mile" of care delivery. These candid sessions delved into health disparities we can no longer ignore and panelists outlined their organizations' efforts to address them. They emphasized that race, ethnicity, gender, income, education and other social determinants help identify these groups' unique challenges so they can be addressed and improve patient health.

3

## **We need nation-wide, disease specific data for every therapeutic area.**

Everyone in healthcare needs access to disease specific data to understand disease origins, rates of occurrence, severity, progression and new therapy effectiveness. From oncology to mental health disorders to infectious diseases, each condition requires unique variables connected in a data set representative of the U.S. population. Once aggregated, we need to "put data to work" answering practical health questions to validate its utility and identify opportunities to improve it.

4

## **Patients are a critical stakeholder in the conversation about health data, and must benefit directly from its use.**

Many expressed opinions about patients' rights with respect to the health data they generate. They range from paying patients for their data to making patients the sole arbiters of its use. We need alignment on how data serves patients and society. Engaging patients and the public in the health data dialogue about the value and use of patient data helps build public trust. The panel on decentralized clinical trials noted that this new approach to research is empowering patients through real time access to their own data. Many expressed that there is a public health imperative for access to aggregated health data for research on fatal diseases, to shape health policy and care for vulnerable populations. So we need to find a way to do this while protecting patients and supporting them with their own data as they make decisions about their health.

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5

## **We need a more robust national health data infrastructure, with a framework that can be replicated across diseases.**

One of the themes that reverberated across panels was an appeal to regulators for guidance and leadership in the use of connected health data. A federal agency or other public / private collaborative should be formed with a governance model that solicits perspectives from all stakeholders in the healthcare ecosystem. It should have access to logistical resources (similar to FEMA) to establish a national health data infrastructure, data strategy and data governance with emergency powers during health crises. It should have the regulatory authority to set clear standards for patient privacy and security. During the panel on privacy, ethics and patient benefit, one speaker suggested the agency should be modeled after the FDA which applies a risk-benefit decision making approach and takes public comment on regulations and guidance documents. This group should set standards for health data including data definitions, and data quality standards so that everyone can trust the results.

## Conclusion

Coming out of Summit, it's inspiring to see how the health data ecosystem has evolved with new data, approaches and organizations committed to improving patient health. The last two years have also raised the urgency of creating a national connected health data infrastructure. As more health data has become available, many want regulatory clarity in areas like privacy and data for evidence generation. We need leaders committed to navigate the complexity of healthcare and engage public and private stakeholders in the healthcare ecosystem. Together, we can carve a path that leads to a healthcare future where we all participate and benefit - empowered with the data needed to make the decisions that improve everyone's health outcomes.