

Extenuating Circumstances:

Data Sharing: Leading Data-Driven Population Health

By Emily R. Griese, PhD; Benson S. Hsu, MD, MBA, FAAP; and David A. Pearce, PhD

Healthcare systems able to effectively leverage their data in the application of advanced analytics are uniquely positioned to innovate the way they provide health care. Health care data, however, is often highly unstructured, requiring a unique skillset to manage and analyze it for innovative application. This becomes a barrier as well-trained data scientists are often difficult to recruit and to date haven't had a direct pipeline for their expertise within the health care sector. Fortunately, the upper Midwest is uniquely positioned at an intersection of academic institutions with nationally recognized data programs, opening the door for collaboration with researchers leading their fields in advanced analytics. Thus, programs such as the Sanford Data Collaborative, a first of its kind data sharing initiative that places real-life, timely health care data in the hands of leading researchers with the ultimate goal of driving health care delivery to transform community health, are well positioned for success.

The success and growth of data sharing initiatives like this hinge on expertise found both internal and external to an institution. Internally, appropriate legal provisions and review processes are of utmost importance prior to data distribution to ensure the highest level of patient privacy. Infrastructure must be in place to protect the release of all datasets including an ironclad data usage agreement with provisions to safeguard data transfers and use. Externally, public expertise should be sought in the creation of a privacy board, or a body designed to review projects with the privacy of the community in mind.

Partnering with external academic institutions who have an existing structure to uphold research integrity (for instance, through institutional review boards) is further crucial to providing the necessary foundation for successful data sharing. The Sanford Data Collaborative looked to foster lasting partnerships across regional academic institutions and sought guidance from academic leaders to

serve on an advisory board and help identify population health topics that would be beneficial to researchers and communities alike. By further serving on an advisory board, academic leaders have the ability to provide crucial expertise on the potential impact of data sharing for their institutions as well as for their communities and region. Additionally, direct meetings with academic researchers provide an opportunity to discuss project ideas and available data elements. These meetings also presented an opportunity to reiterate the need for truly multidisciplinary teams that can bring diverse expertise (i.e., data science, pharmacy, nursing, business, health informatics, etc.) both in advanced data analytics but also in translating its impact for innovative healthcare delivery. As such, teams with multidisciplinary expertise willing to identify novel approaches to population-level data sets are most likely to be successful as a data sharing partner.

Equally important to building collaborative relationships externally is the need to build a collaborative internal infrastructure. For the Sanford Data Collaborative, key leadership from across the enterprise, spanning research, data analytics, health plan, and health care delivery, were brought together to identify priorities and to create a process that could push past research for research sake and work to translate innovative advanced analytics solutions into clinical application and ultimately positive community health impact. As such, along with an analytics phase there is a need to move towards validation (see Figure 1), where researchers have the opportunity to confirm findings within a healthcare system, providing evidence for future studies and data to further pioneer improvements in health care delivery.

It is evident that data sharing with the appropriate structures in place can bring healthcare systems to the forefront of health care innovation. Advanced analytic modeling focused on predictive risk stratification, chronic disease management, diagnostic testing strategies, or

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Figure 1. Data Collaborative Phases



technology utilization, for example, has the potential to sharpen data-driven provider practices, applying algorithms that can offer increasingly robust evidence upon which care decisions can be made – more precisely and efficiently. The ability to predict and prescribe health care at the population level through the application of existing big data further opens a new door for health care delivery and its impact on community health outcomes. As such, success for the Sanford Data Collaborative is in bringing together multidisciplinary teams of researchers and clinicians to leverage population-based data, driving an integrated vision to further understand and impact of the larger healthcare environment within our communities.

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