

Toward a Health Data Strategy for North Carolina

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In recent years, North Carolina has attracted significant national attention due to numerous health care reforms underway across government and the private sector. These reforms encompass new incentives, new partnerships, and new models of delivering care, and collectively, they have important implications for health care data.

This article reviews a recent panel discussion as part of the National Academy of Medicine (NAM's) November 2019 health care symposium ("Vital Directions for Health and Healthcare: The North Carolina Experience"), which included provider, health plan, and government perspectives [1]. This article aims to briefly synthesize key points from the panel discussion.

Background

North Carolina's health care landscape is rapidly changing. First, the state's Department of Health and Human Services (NC DHHS) is shifting the NC Medicaid program, which serves over 2 million people, toward a system of managed care. This transition, which is subject to further deliberations over the state's budget, encompasses multiple complementary reforms. First, NC DHHS is establishing pathways for provider organizations to participate in a range of new care and payment models through a new Advanced Medical Home (AMH) program. The AMH program allows physician practices, groups of clinics, and health systems serving Medicaid beneficiaries to elect progressively greater levels of responsibility for overall population-level health outcomes and total cost of care and receive new resources and flexibility to assist in bearing this responsibility.

Second, NC DHHS is restructuring Medicaid benefits to integrate medical and behavioral health to better coordinate services and improve health and fiscal outcomes. And third, the state is working with multiple stakeholders to organize new resources to address non-medical factors that influence health, such as housing, food, and transportation, to benefit all North Carolinians. These and other changes encompass an ambitious Medicaid transformation agenda that will be implemented with the transition to managed care.

Meanwhile, Community Care of North Carolina (CCNC), the longstanding nonprofit organization that has histori-

cally provided care management services for the Medicaid population, is now redefining its role to strengthen partnerships with providers and expand its work to other payers and populations.

For its part, North Carolina's largest health insurer—Blue Cross and Blue Shield of North Carolina (Blue Cross NC)—is launching an array of complementary initiatives for millions of members with commercial or Medicare Advantage coverage [2]. Blue Cross NC's "Blue Premier" program represents a partnership between Blue Cross NC and providers—including large health systems as well as independent practices—to identify and jointly pursue cost-saving opportunities that can also improve patient health and outcomes [3]. These partnerships encompass new data-sharing and clinical collaborations and a shift toward new payment models that allow participating providers, and, most importantly, patients, to share in cost savings that improve the health of patients and populations.

Blue Cross NC has unveiled a range of innovative partnerships in support of these goals. Through its partnership with Aledade, Inc., Blue Cross NC is making it easier for primary care practices to remain independent and benefit from the savings generated through improving access to robust primary care and keeping patients healthy at home [4]. In collaboration with Quartet Health and Eleanor Health, Blue Cross NC aims to facilitate access to high-quality care for behavioral health and substance use disorders, and to improve care coordination and communication among providers. And through partnerships with Cityblock Health, Iora Health, and CareMore, Blue Cross NC is testing new primary care-focused models of care throughout the state.

Meanwhile, a growing number of health systems and independent providers are participating in alternative payment models with Medicare and additional private insurers operating in North Carolina, such that we may be reaching a critical mass of financial incentives aligned toward trans-

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forming health care delivery in an effort to pursue better health at lower cost.

All of this (and much more) is happening at a time of ongoing legislative deliberation about Medicaid expansion, multiyear efforts to fight the opioid epidemic (and now the COVID-19 pandemic) at the state and local levels, ongoing industry consolidation affecting hospitals, practices, and health plans, and active speculation about what the 2020 elections will mean for health care in North Carolina and beyond.

In this frenzy of activity, what health care data infrastructure is needed to make these and other health care reforms successful?

Toward a Data Strategy for North Carolina

Our “True North”: Health, Patient Experience, and Affordability

Our Vital Directions panel first discussed how a North Carolina health care data strategy should be calibrated to achieve specific goals. Panelists agreed that such a strategy should be engineered to facilitate specific improvements in patient and population health, affordability, and patient experience. These goals can be made more specific, measurable, and time-bound, but, ultimately, as NC DHHS Secretary Mandy Cohen outlined in her keynote address earlier in the symposium, health is the “true north” on which our investments and activities should be focused [5].

Regarding the goal of affordability, panelist Patrick Getzen of Blue Cross NC noted that if health care premiums rise by 6%-8% per year on average while salaries and wages go up only by 2% to 2.5%, “you don’t need a designation as an actuary to understand that over time, that’s an unsustainable cost model” [6]. Getzen described ongoing efforts to examine the percentage of household incomes in North Carolina that are consumed by health care premiums and out-of-pocket costs, describing the results as “startling.” Panelists agreed that focusing on defining and improving affordability should be an important dimension of the state’s health care agenda, and therefore an important dimension of the state’s health data strategy.

Grand Vision Facilitated by Incremental Progress

A second key theme from our panel involved the juxtaposition of developing a long-term data vision with a practical and relentless focus on making steady progress on a near-term basis. Entities throughout the North Carolina health care ecosystem—whether health systems, independent practices, technology and service providers, payers, employers, government agencies, or researchers—envision a world in which all kinds of medical, social, and other data are neatly and accurately combined; readily and securely available for a wide variety of use cases; and efficiently and reliably accessible and integrated into clinical workflow. These are important ideals, but they are not the present

reality. Given the myriad information needs we have now, we can’t wait until we have a data panacea to make practical, stepwise progress.

A long-term vision for data access and integration for North Carolina is important and necessary, but it can be easy to get bogged down in day-to-day questions of data governance, legal challenges, technical limitations, and resource constraints. Forward progress requires deliberate prioritization and focus, or what we might call “radical incrementalism,” in which steady, measurable progress can be made toward a longer-term data strategy. This means keeping a larger vision for data integration and governance in mind, while gaining consensus about the most important near-term questions to answer and problems to solve, devoting necessary resources to effectively address them, making necessary adjustments in partnership with end users, then moving on to new and often harder use cases that build toward the longer-term data vision.

Identifying the Most Important Questions to Answer and Problems to Solve

For data and technology to play a more meaningful role in improving population health, enhancing affordability, and improving patient experience, we must be specific about our priorities: What are the most important questions to answer *right now*? What are the most important problems to solve *right now*? Structuring a data strategy around solving real problems in the short run, iterating on those solutions with practical feedback from end users and beneficiaries (e.g., patients, providers, insurers, and government), and building incrementally will likely get us further faster than tackling a grand vision all at once.

Our panel explored examples of some of the most pressing information gaps that, if addressed, can help fuel North Carolina’s health care transformation to improve patient health, patient experience, and affordability. Here, we highlight three examples:

Information challenges affecting patients. The panel highlighted a number of basic data infrastructure needs from the patient perspective, drawing on panelists’ experiences as health care leaders and as patients and caregivers. In general, patients want to know how much a health care service is going to cost, and they want their physicians to be knowledgeable about patient costs when considering treatment options. This may also include valid and timely information about the breadth of their insurance plan’s provider networks so they are not exposed to unanticipated costs when undergoing treatment or receiving care.

Patients generally want and expect all members of their care team to communicate with each other. Patients want and expect their primary care provider to be in the loop if they go to the hospital and to know everything they need to know about that hospitalization when they go home. Finally, if there is a service available to a patient that she or he could

benefit from, whether related to medical care, behavioral health care, or social needs, patients generally want to know what it is and how to access it.

Panelists pointed out that these expectations are valid and important to achieving our goals, yet are not part of today's health care system, with limited exceptions. We can do better.

Information challenges affecting clinicians. Many of the same basic informational needs that frustrate patients would also be cited by clinicians and care team members involved in value-based payment models as information barriers that need to be addressed. In addition, providers must bear the time and financial costs of inefficient flows of health care information across different electronic health record (EHR) systems and applications; lack of standardized formats and processing delays for administrative data from payers; and a multitude of disparate quality measurement and reporting requirements across health plans.

Panelists highlighted the example of real-time event notification (i.e., timely alerts that help care team members understand the location and status of their patients). North Carolina hospitals have had the technical ability to share such admission, discharge, and transfer (ADT) data feeds for several years. Yet, depending on where they practice in North Carolina, community-based primary care providers, behavioral health providers, and other entities who are part of the care team still cannot be assured that they will be notified when patients are in a hospital or nursing facility and when they are coming home. The technology is there; we can do better.

Provider organizations have a statutory mandate in North Carolina to submit certain data elements to the State Information Exchange (NC HealthConnex) as a condition for treating patients with state-financed coverage, but many hospitals and health systems in North Carolina still do not participate for all patients, choosing to narrowly comply with state regulations around state-financed patients only, rather than supporting the use of NC HealthConnex as a statewide utility for the benefit of all. Large health systems may cite their collective participation in Epic Care Everywhere (which allows for entities with an Epic EHR system to access information from other Epic hospitals) as meeting their own needs. Yet the absence of a comprehensive, whole-population solution for event notification across the health care ecosystem puts patients at risk and impedes progress toward the goals of better health, lower costs, and better patient experience, illustrating the challenge of relying on voluntary collaboration around data sharing. Greater support for NC HealthConnex as a public health utility over time will ease data-sharing burdens considerably.

New federal rules implemented by the Trump Administration as part of the federal 21st Century Cures Act (2016) strengthen regulatory requirements for more robust hospital participation in data exchange in the near future

[7, 8]. The Cures Act requires health plans, hospitals, and states to adopt specific mechanisms of data sharing with patients who can grant access to their own health information to organizations and applications they trust.

Information sharing between health plans and providers in value-based payment arrangements. The panel discussed information needs created by new payment arrangements between providers and health plans. Provider organizations (hospitals, health systems, physician practices, and federally qualified health centers) cannot effectively accept accountability for patient and population health outcomes without relevant, timely information about the patients for whom they are accountable. In addition to clinical data available through electronic health records, such entities need to be able to leverage the full picture of health care utilization (claims) data to identify opportunities for improving care and reducing waste, and they need to fully understand how health care resources are being used in order to make sound business and clinical decisions.

Health plan leaders on the panel described steps being taken to overhaul data-sharing approaches with provider organizations participating in new payment and care delivery arrangements. As part of the Medicaid reforms launched by NC DHHS under the AMH program, health plans will be required to share claims information in standardized formats with certain provider organizations participating in alternative payment models. On the commercial side, health plans are actively collaborating with provider organizations to improve the flow of data and data insights. In collaboration with the Duke-Margolis Center for Health Policy and NC DHHS, for example, health plans like WellCare and health systems like UNC Health are working together to pilot new streamlined bulk data-sharing standards and strategies (i.e., the so-called Fast Healthcare Interoperability Resources standard, or FHIR) aiming to ease the administrative burdens and costs of business-to-business data sharing while enhancing data security when care team members responsible for patient outcomes share sensitive data.

One key takeaway from the panel was that health plans cannot adopt a "take it or leave it" approach to data sharing with their business partners or patients. Respecting the fact that the typical physician often serves patients from dozens of different insurance arrangements, ongoing iteration and testing is needed between plans and providers acting as business partners to get the consistent data contents, standards, and data sharing frequency right and most effectively serve population health goals. Longer term, this is also an important opportunity for NC HealthConnex to consolidate data feeds and access points.

Leadership is More Important than Technology

A final cross-cutting theme that emerged from the discussion was the importance of leadership and trust to enable more widespread data sharing. From a strictly technical per-

spective, many of the data gaps the panel identified are not particularly daunting to address. For example, the industry has long achieved solutions for the ADT notification problem cited above. The data-sharing problem is not a technical or regulatory one; it is a matter of leadership and, in particular, of will. As Secretary Cohen emphasized in her remarks at the Vital Directions symposium, data sharing proceeds at the “speed of trust” between stakeholders who must be committed to working together on behalf of the broader goals of health, affordability, and patient experience [5].

When the entities involved have the will and the means to cooperate, technical problems can be solved. Waiting for voluntary cooperation on the premise that it’s the right thing to do, however, may not be enough. We are already seeing that aligned financial incentives under value-based payment models bolster cooperation and partnership. But in some important cases, we also know that further policy and regulatory steps may be necessary to accelerate progress for the benefit of the whole population.

Conclusion

In summary, our NAM panel discussion focused on motivating investments (of time and money) and actions toward the “north star” goals of better health, affordability, and patient experience.

Second, we described the need for a long-term data strategy in which a wide variety of health-related information can seamlessly and securely flow to key stakeholders, to support various important use cases. But there was consensus on the need to build trust through relentless focus on solving real, near-term problems and answering real questions with data that can inform business and clinical decisions and improve outcomes in the near term.

To this end, we explored several examples of important data-sharing needs to ensure the success of numerous reforms underway; opportunities for voluntary industry business partnerships or new regulatory action to spur progress; and the need for leadership and cooperative will to realize the full potential of data and technology to advance the goals of health reform. **NCMJ**

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