

2024

Creating a Primary Care Focused Health System

A New York State Data Report

PCDC.org



INTRODUCTION

Primary care is essential. Access to high-quality primary care saves lives, leads to better individual and community health, is unequivocally central to health equity, and reduces overall health care costs. (i) Primary care is a cornerstone of vibrant, thriving communities and helps keep families healthy, children ready to learn, and adults able to pursue education and participate in the workforce. Nationally, primary care accounts for approximately 35% of all health care visits each year – yet only about 5 to 7 percent of all health care expenditures are for primary care. (ii) To identify programmatic and policy priorities that would help increase access to primary care for all New Yorkers, measure the impact of policy changes, identify areas of need, and measure future progress, high-quality health care data are critical.

Data and evidence play a critical role in highlighting the need for primary care. In December 2024, PCDC's Annual Primary Care Summit focused on the role of data in creating a primary care-centric health system (Appendix A). Gathering health data experts from New York State and around the country to share their perspectives on existing challenges, best practices, and hopes for the future provided PCDC with important insights about the way health care data could help advance better health access and outcomes in New York and surfaced some of the barriers to achieving those goals today. The summary below lays out learnings from other states and recommendations for New York from the Summit.

LEARNINGS FROM OTHER STATES

A health data ecosystem can take many forms. Establishing such a system requires a clear vision, strong leadership and stakeholders who have buy-in to the system's success. Across the country, states are in different stages of creating and using their health care data systems. In addition to providing public use datasets, some states are also linking various datasets for more robust analysis:

- Colorado: The Center for Improving Value in Health Care in Colorado released limited datasets from their All Payer Claims Database (APCD) to broader stakeholders.
- Arkansas: As part of the Arkansas Healthcare Transparency Initiative Act, the data infrastructure integrates claims-based data from commercial insurers and public payers with non-claims-based health data from partnering agencies, to understand trends in health outcomes, and acknowledge that one dataset alone is not capable of answering all health care utilization questions.

- Massachusetts and the Center for Health Information and Analysis (CHIA), an independent organization that was set up explicitly to help with the state's health care data, have been leaders in this area. They have shown how an independent state agency can bring health care data sources together and use data systems and products to promote purpose and accountability within the health system. CHIA regularly measures primary care spending and reports on where and how money is spent in Massachusetts. In 2023, CHIA published the first-ever state Primary Care Scorecard. Currently, CHIA has several years of data that they are able to tabulate and present, including disaggregating for adults and pediatrics. These data have been used to help advocate for primary care spending targets and other primary care policies. CHIA also examines consumer data every other year, including barriers to access, usual source of care, and reasons behind not seeking care, allowing them to show trends over time.

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In New York, the health infrastructure includes different data systems that capture health care data, including the All Payer Claims Database (APCD), the Statewide Planning and Research Cooperative System (SPARCS), the Quality Assurance Reporting Requirements (QARR), and the Statewide Health Information Network for New York (SHIN-NY). Currently, the data provided to the APCD is not publicly available, although the NYS DOH periodically publishes reports aggregating different pieces of the data. According to the NYS DOH, their goal is to make data from the APCD more readily available over time.

RECOMMENDATIONS

PCDC recommends that policymakers and stakeholders in New York consider the following key ideas for the future – ideally, the not-too-distant future, as there is an urgent need to move towards a more effective and equitable future.

Public availability and utility of health care data that can inform better access to and higher quality care, particularly primary care: New York State was one of the first to enact legislation creating an APCD, designed to help researchers, policymakers and health care providers understand health care spending - and in turn, utilization, access, accountability, price fairness, and a host of other implications. However, this database still remains unavailable to the public fourteen years later.

State officials have made key data points available, releasing it in the form of dashboards and graphics. Nonetheless, more is needed. Health care data is essential for health system improvement, to understand the current state in order to move towards a new one.

“You can’t increase how many steps you’re walking in a day by 10% if you don’t know how many steps you’re walking now.”

- Erin Bonney, Director of Health Informatics and Reporting, Center for Health Information and Analysis (CHIA)

PCDC joins other advocates (iii) in recommending that the APCD be made publicly available in the future.

- Asking the right questions of the data is just as important as having access to the data in the first place: Having access to the data will not be sufficient to improve access or quality. The next step, asking the right questions of that data to reveal actionable information, is equally critical.
- PCDC recommends that: (1) stakeholder engagement begin immediately, and (2) a wide net be cast for relevant stakeholders to ensure that the right questions are being asked to reveal the most useful answers.
- Paying attention to patient privacy and patient data with multiple data sources and in an age of AI : As more sources of data become integrated and new technologies are added to the provision of health care, patient information may become more porous and harder to protect.

While public-facing data is critical to inform policymaking and more localized decision-making, individual patient privacy continues to be a paramount concern for policymakers and providers. At the same time, market forces have led to health care data being widely available for sale and used by private actors, whereas states, researchers and nonprofits often have less access. Learning what can be done to mitigate those potential harms while ensuring that states, providers and policy analysts and advocates have access to the best data to inform decision-making is important.

PCDC encourages policymakers to center patient privacy in their decisions and consult technology and market experts to understand how patient data is being used, sold, and exposed while providing public data to the greatest extent possible.

APPENDIX A – SUMMIT OVERVIEW

In December 2024, PCDC invited experts from New York State and around the country to PCDC's annual Primary Care Summit to share their perspectives on how to make data on health care access, quality, and cost more available in New York.

Panel discussions identified best practices from other states, barriers and recommendations on improving the health care data infrastructure in New York and shows how allowing access to this data is essential to increase primary care access, reduce costs, and promote public transparency and accountability.

Panelists included:

- Oxiris Barbot, M.D., President & CEO, United Hospital Fund
- Susan Beane, M.D., Vice President and Executive Medical Director, Healthfirst
- Erin Bonney, Director of Health Informatics and Reporting, Center for Health Information and Analysis (CHIA)
- Louise Cohen, CEO, Primary Care Development Corporation
- Sherry Glied, Ph.D., Dean of the Wagner School of Public Service at New York University.
- David Horrocks, CEO, New York eHealth Collaborative
- Kevin McAvey, Managing Director, Manatt Health
- Anne Schettine, RN, Director, Office of Health Services Quality and Analytics, New York State Department of Health

FOOTNOTES

i Friedberg, M. W., Hussey, P. S., & Schneider, E. C. (2010). Primary care: a critical review of the evidence on quality and costs of health care. *Health Affairs*, 29(5), 766-772.

ii McCauley, L., et. al. Chapter 3: Primary Care in the United States: A Brief History and Current Trends. In: McCauley, L. et. al, eds. *Implementing High-Quality Primary Care: Rebuilding the Foundation of Health Care*. Washington, D.C. National Academies Press; 2021:71-92.

iii Why is Health Care in New York So Unaffordable and What Can be Done to Fix It?, https://smhttp-ssl-58547.nexcesscdn.net/nycss/images/uploads/pubs/012925_NYS_Overview_Brief_V7.pdf.

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