Although the government spends more on Medicare than it does on Medicaid, Medicaid is the government-funded health insurance program that covers the most people in the US (Medicaid insures more than 77 million people). There could be great value to improving the quality, effectiveness, and targeting of care delivered through these programs, making assessments of both government programs important to researchers and policymakers. However, efforts to evaluate and improve Medicaid and the Children’s Health Insurance Program (CHIP) are hampered by fragmented data collection efforts and limited capacity within states to analyze their own data. This is particularly unfortunate given how much could be learned about how to improve the design of these programs.

Unlike the federal Medicare program that has limited variation in the implementation of the program, Medicaid varies from state to state, providing a laboratory for learning what works best for beneficiaries. However, limited information is available about the program experiences of Medicaid enrollees and how demographic characteristics, social risk factors, and program characteristics affect the care and health of enrollees. Rectifying this data gap could accelerate innovation and improve quality and value for patients, clinicians, and taxpayers.

The data available for Medicare are instructive, and include traditional fee-for-service Medicare capture payments and the services used from claims; there are now similar encounter data for Medicare Advantage managed care plans. However, these utilization data do not capture patient experiences with care, realized access and unmet needs, or self-reported health outcomes. The Medicare Current Beneficiary Survey (MCBS) captures information about the medical and social determinants of health, self-reported health outcomes, and a wide range of other variables for Medicare enrollees. The MCBS is linked to Medicare claims data to help researchers understand how these factors interact with patterns of health care use, and ultimately, health outcomes.

The Medicare Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey captures beneficiary experiences in Medicare Advantage plans and, more recently for Medicare fee-for-service and Medicare prescription drug plans. The Medicare CAHPS surveys measure aspects of enrollee experiences with physicians and health plans that are not measured in other ways. For people navigating acute and chronic health conditions, the CAHPS surveys provide data on ease of obtaining specialty care, experiences with care coordination, physician communication, and receipt of recommended services. Medicare CAHPS data are used for public accountability, quality improvement projects, and value-based purchasing efforts. Similar to the MCBS, the CAHPS survey is linked with claims data and other sources such as the Surveillance, Epidemiology and End Results (SEER) cancer registry data (SEER-CAHPS). Because the MCBS and CAHPS surveys are conducted annually, there is a longitudinal record of program performance that captures demographic shifts in the US population and important historical events (such as the COVID-19 pandemic) and program evolution. These data enable researchers to address a wide range of questions, producing invaluable information for program administrators and legislators.

Medicaid data availability is markedly different. Until recently, it was difficult to get harmonized utilization data about state Medicaid programs. The Transformed Medicaid Statistical Information System (T-MSIS) has created opportunities to draw on data across states, which is a major step forward for evidence-based policymaking. Efforts to improve the quality of the data are paying off, facilitating the development of evidence-based best practices and standards for key areas of
concern, such as maternal health and substance use disorders. But data are still lacking on the perspectives of patients, which could provide information about their experiences with Medicaid to clinicians and policymakers. Although Medicare uses the annual MCBS and CAHPS beneficiary surveys, Medicaid has had only 1 snapshot national survey (the Nationwide Adult Medicaid CAHPS) that was conducted a decade ago.

Medicaid disproportionately serves individuals from marginalized groups (eg, those with low incomes, racial and ethnic minority groups, or those living in rural isolation) who often have worse health outcomes than the general population. The Medicare program is federally administered and has many powerful constituencies. Medicaid is a federal-state partnership with considerable flexibility within each state and lacks strong consumer advocacy. Transparency about the quality and the experiences of beneficiaries is essential for accountability to taxpayers, enrollees, and policymakers.

There is quite a bit of evidence, for example, that insurance design choices (such as ease of enrollment processes, coverage rules, clinician payments, or utilization management tools) beyond basic eligibility requirements very much affect the use of services and health outcomes. The possibility of improving outcomes without additional spending is the central argument underpinning Medicaid innovation waivers. High-quality survey data would allow evidence-based policy decisions about such waivers, which would be particularly useful given that most states have constitutional balanced budget requirements that require them to show budget neutrality when experimenting with Medicaid policy.

In 2023, the Medicaid and CHIP Payment and Access Commission recommended to Congress that the Centers for Medicare & Medicaid Services conduct a federally administered annual beneficiary survey. The Centers for Medicare & Medicaid Services took a step in this direction in April 2024 when it issued a new final rule that requires states to administer annual beneficiary surveys for enrollees in managed care. These surveys are meant to inform state Medicaid programs about how well comprehensive managed care plans are serving beneficiaries; the rule also includes a requirement that states conduct secret shopper surveys and implement a beneficiary advisory group.

Even though this will be valuable information for states to have, the final rule allows states to develop their own surveys and there are no requirements for data harmonization across states, linking to the T-MSIS, or making the data available to researchers, thus greatly limiting the usefulness of the data for the evaluation and assessment of different state Medicaid policies and imposing substantial cost and administrative burden on states. In addition to increasing aggregate sample sizes for subpopulations, a longitudinal harmonized dataset would allow comparisons across states and over time, which is crucial for taking advantage of policy variation to learn about the effects of different eligibility rules, payments, administration, and more. Being able to link survey data to other data sources, including claims data, would dramatically increase the questions that researchers can answer. In addition, uniform implementation through a common vendor would increase usability of the data and the efficiency of conducting the surveys.

Health services researchers have a long history of producing valuable Medicaid analyses for policymakers and administrators—indeed, evaluation is a requirement of Medicaid waivers—but Medicaid data limitations have restricted the lessons to be learned. There remains a large gap in the information available to improve Medicaid relative to Medicare. A new set of Medicaid beneficiary surveys could inform Medicaid policy and research funding from the National Institutes of Health, driving innovation in care delivery and improvements in patient outcomes. Policymakers should take full advantage of this opportunity to improve the research infrastructure for the Medicaid program.
REFERENCES

